

**REVIEW OF ALBERTA HEALTH SERVICES'
CONTINUING CARE WAIT LIST: FIRST AVAILABLE APPROPRIATE
LIVING OPTION POLICY**

March 26, 2014

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FOREWORD

Every day in our province there are individuals grappling with the myriad of challenges that come with making the difficult transition from independent living to facility living in continuing care. This can be a distressing and emotional time.

In this review we examined the quality and patient safety implications of Alberta Health Services' policy "Continuing Care Wait List: First Available Appropriate Living Option". Our findings and analysis discuss critical operational topics such as capacity planning, measurement data, and policy development. However at its core, the report is focused on people. We provide practical recommendations about how the healthcare system can and should consistently respond to patients' and families' needs for an acceptable and appropriate process for decision-making about their future home. We have outlined steps to equip both family members and care providers with tools and information so they are prepared to make these decisions and can support individuals through this challenging transition.

There are many individuals who contributed time and expertise to this review. I would like to thank all of the members of the review team for their diligence in conducting the review, their passion for a quality and comprehensive report, and their commitment to the Albertans we serve. On behalf of the team, I would very much like to thank residents, their families, and all individuals, who participated in interviews, provided documentation, and were readily available to answer questions and provide background information.

The Health Quality Council of Alberta is proud to have supported Alberta Health Services by conducting this review. We commend the thousands of healthcare professionals and support staff who work each day to provide better care for Albertans. We are confident that our recommendations will lead to quality improvements for patients, families and care providers.

Patricia Pelton, Acting Chief Executive Officer, HQCA
Calgary, Alberta
February 28, 2014

EXECUTIVE SUMMARY

On June 18, 2013, Alberta Health Services (AHS) requested that the Health Quality Council of Alberta (HQCA) conduct an independent review of the quality and patient safety implications of the April 2013 AHS policy *Continuing Care Waitlist: First Available Appropriate Living Option* (FAALO).

The Health Quality Council uses the Alberta Quality Matrix for Health to define and assess health system quality. Quality is defined through the following six dimensions: accessibility, acceptability, appropriateness, effectiveness, efficiency, and safety. The matrix provided a platform to understand the quality and patient safety issues related to the FAALO policy and its application in the healthcare system.

This review concluded that:

- A policy and procedure to support fairness in transitioning patients to a continuing care living option is required. The policy development process and the policy elements need to be congruent with AHS values.
- An underlying assumption is that patients facing this transition should have some degree of choice in determining a living option. The transition experience should provide sufficient time and information for patients and families to make an informed decision about their future living option.
- There is generally a wait to transition to a continuing care living option. This results in patients being cared for in a less than optimal environment to meet their needs. Further, if the patient is waiting in acute care, there is a downstream impact on those needing hospital services. In order to manage this capacity challenge and better align resources now and in the future, appropriate use of data and demand/capacity modeling is required.

Methodology

To meet the Terms of Reference for this review, as shown in Appendix I, the HQCA's Quality Assurance Committee (QAC) conducted a review under section 9 of the *Alberta Evidence Act*. The review included:

- Current but not operational AHS FAALO policy
- FAALO policies in the legacy health regions in Alberta
- Similar FAALO policies in Canada and elsewhere
- Client experiences with FAALO policies in Alberta
- Effect of FAALO policies on the performance of the continuing care system and the broader Alberta health system

A mixed methods approach was used to gather information to meet the review objective. Information was gathered from a number of sources:

- **Environmental scan** of other Canadian provinces and territories and their approach to continuing care placement.
- **Documentation review** included those provided by interviewees as well as other documents acquired through Internet searches.
- **A review of the literature** on the topic of continuing care wait list management and the impact of continuing care placement on individuals.

- **Semi-structured interviews with key informants and experts** across the health system to discuss the evolution of and challenges with the FAALO policy.
- **Semi-structured interviews with a purposive sample of residents (or family members)** currently residing in continuing care and placed initially in one of their preferred options or were required to take the first available appropriate living option.
- **Review of current AHS data and performance indicators** for continuing care wait list management (capacity and demand).
- **An expert in operations management research** was consulted.

Background

Continuing care in Alberta is defined as a range of healthcare services including home care, supportive living (with four levels of care, at home or in a facility), and long-term care in nursing homes or auxiliary hospitals. People access continuing care from home, hospital, or another continuing care facility.

Various policies have been in place since 1993 that set out how patients access continuing care in Alberta. Most of the legacy health regions established their own wait list management policy or protocol as early as 1997, including placement in a first available living option. When AHS became an entity in 2008, work began on a province-wide policy, which resulted in the FAALO policy that is the focus of this review. The FAALO policy was developed as part of an over-arching policy to address capacity issues that affect the flow of patients in the healthcare system.

According to the FAALO policy, if a patient's preferred location is full, the patient "shall be temporarily admitted to the first available appropriate site or location as near as possible to the patient's primary preferred site(s) or location" until a space opens. The policy states that the temporary site is to be no farther than 100 kilometres from the patient's home or preferred site. A companion document, the Continuing Care Waitlist: Prioritization policy, ensures that patients who have agreed to a first available space will have priority for moving into a preferred location when space becomes available.

In June 2013, AHS withdrew the policy, initiated an internal policy review, and requested the HQCA conduct its independent review of the quality and safety implications of the policy.

Findings

Shortcomings in policy and information to support the transition into continuing care

Despite years of attempts, and multiple policy drafts, a province-wide FAALO policy is not in place. As a result, the way in which patients are transitioned into continuing care living options varies widely throughout Alberta.

Current government strategy is consistent with established research in its emphasis on supporting seniors and people with disabilities to remain in their own homes and communities. The importance of allowing people to choose where they would like to live is also recognized. Alberta lacks sufficient capacity to accommodate everyone waiting for placement to a continuing care living option, however. This creates the need for a wait list, but also for flexibility to care for people in temporary sites until space is available in their preferred location. It is critical that this process be managed well, because when it is not, person-centred care suffers and there are ramifications to the healthcare system as a whole. This can result in a backlog of patients waiting in hospitals and occupying beds needed by others, and patients being moved to a non-preferred living option.

This review found that the healthcare system is unable to consistently respond with a transparent process that patients and their families find acceptable or appropriate when moving to a continuing care living option. Many people interviewed during this review, including patients and families, emphasized that while they understood the need for a policy, the way in which transition occurred and the limited discussion about it made the process difficult for them. Families felt rushed to make a decision, with inadequate information made available to support them in doing so. Vital information, such as services available and wait times for individual sites, was not readily available, nor did families feel they were sufficiently consulted about their preferences. Some felt pressured into accepting an offer of placement that they felt did not meet their needs, and felt there was no recourse available to them if they were dissatisfied.

Issues with planning and management of continuing care capacity

There is ample evidence within Alberta that effective long-range planning for continuing care capacity can have measureable, positive outcomes in all parts of the healthcare system. Historically and currently, to varying degrees in each AHS zone, continuing care capacity has failed to meet demand.

Managing the continuing care system capacity requires an understanding of the factors that determine the number of patients who are on a wait list and the average time on that list, which are best understood using queuing theory⁴. These factors include:

- Number of people requiring a continuing care living option (demand).
- Available continuing care living options (capacity), which is dictated by the total number of living options available and residents' length of stay (LOS).
- Variability in demand and available capacity over time.

Continuing care capacity should be managed using data on the past and current state of supply and demand. In addition to monitoring the current state, effective managing also means examining forecasted demand and capacity over the short term, intermediate, and long term. These forecasts should consider modeling based on operations management principles to determine the anticipated size of a wait list and length of wait times.

The HQCA commends AHS for the considerable work that has been done to date and recognizes the associated challenges, especially when the data required to support forecasting are incomplete. For several years AHS has taken a more disciplined and proactive approach towards forecasting continuing care resources and has added supportive living spaces throughout the province. Prediction models have been created by AHS that look forward to 2032. These provincial models have used data on available continuing care resources with adjustments for the current shortfall in numbers of beds and the ratio of different types of beds. The models have also incorporated demand forecasts based on projections of

⁴ This is explained in detail in the Findings section of the report.

population growth, changes in aging demographics, and predicted changes in underlying disease complexity.

Although this type of modeling represents a considerable improvement in planning compared with previous efforts, it was recognized that the modeling may not be as robust as it could be for the substantial investment in infrastructure and human resources that is thought to be needed. Predicting the future is difficult. There are, however, well-established methods, taken from the science of operations management, for increasing the usefulness of prediction models, which are discussed in detail in Findings.

The full report provides detailed findings and analysis from the various avenues of enquiry. Readers are specifically referred to Appendix V that describes the experiences of patients and families.

Issues, recommendations, and required actions

The review identified two key issues, with associated recommendations and required actions that offer opportunities to improve the quality of care and transitions for patients accessing a continuing care living option. A full discussion of the issues, analysis, recommendations, and required actions can be found starting on page 58 of the report.

Issue

Making the transition to a continuing care living option is a significant life event. The healthcare system is unable to consistently respond with a transparent process that patients and their families find acceptable or appropriate.

Recommendation 1

Alberta Health Services develop and implement a:

- provincial *policy* for transitioning people to continuing care that:
 - assures principle-based decision making
 - incorporates elements that are congruent with AHS's stated values, and excludes elements that appear threatening or punitive
 - recognizes that in circumstances where due process has been followed and an acceptable solution cannot be reached, AHS has the authority to move the patient to a safe and appropriate living option (per Alberta Hospitals Act),
 - includes the right of appeal
- consistent and transparent provincial procedure for transitioning people to continuing care that:
 - provides strong decision support to assist patients and caregivers to specify their preferences
 - specifies when and how patients and caregivers will be presented with all appropriate living options that best match their preferences and assessed need
 - specifies reasonable timeframes for patients and caregivers to make decisions about the presented options

- describes a resolution mechanism when the presented options are not acceptable
- ensures those patients who are placed in a non-preferred living option continue to be supported, making it possible for them to transition to their preferred option at a later date

Required actions

- Include patients and caregivers and operators of continuing care services as key stakeholders in the development of the procedure and policy.
- Develop a decision support tool that incorporates the factors considered by patients and caregivers when naming their preferred continuing care living options (e.g., location, distance, cultural, language, and environment).
- Integrate the new procedure and policy with the AHS Continuing Care Waitlist: Prioritization policy.
- Undertake formal deliberative ethics input to the policy and procedure development that:
 - includes patients, families, caregivers, and other stakeholders.
 - specifies the ethical principles that underpin the policy and procedure elements.
 - describes how these ethical principles are balanced and apply to the decisions that patients and caregivers, as well as providers, encounter throughout the entire transition process.
- Develop an evaluation plan to determine and monitor the impact of the policy and procedure on patient experience and the quality and safety of care.

Recommendation 2

Alberta Health Services develop information that meets patients' and caregivers' needs and supports their ability to make informed decisions about available continuing care living options.

Required actions

- Collaborate with patients, caregivers, and continuing care providers in the development of the information, its dissemination and ongoing maintenance.
 - information provided could include: support services provided, wait time, age and size of facility, room configuration (e.g., single or shared, windows), cultural/language focus, location, additional costs, quality ratings/measures, aging-in-place options, pet policy.
 - information should be readily available in various formats (e.g., hard copy, on-line).

Issue

Historically and currently, to varying degrees in each AHS zone, continuing care capacity has not adequately met the need (demand) for these services. Measurement of variability in demand and in capacity is critical to the understanding and management of intermediate to long-term continuing care resources. Current reporting and modeling may not be sufficiently robust to fully support continuing care capacity management and forecasting functions.

Recommendation 3

Alberta Health Services create and use specific demand and capacity performance measures that will support decision-makers to manage the wait lists for continuing care.

Required actions

- Where data do not currently exist on continuing care capacity (e.g., percent occupancy), develop data sources and methods for validation, then use AHS Data Integration, Management and Reporting's automated data reporting to make this readily available to accountable decision-makers.
- Create automated graphical data reports to optimally support AHS decision-makers' ongoing management of current resources. Such reports should display: 1) current and past state of the queues for continuing care services and the impact this is having on other parts of the healthcare system; 2) current and past demand and capacity data (and the degree to which they match); and 3) the extent to which current state compares with forecasted demand and capacity. For example, for each of the four types of continuing care living options for each AHS zone or service delivery area and, where relevant, for populations with specific conditions (e.g., patients requiring dialysis, ventilators, or programming for dementia-related behavioural challenges) develop graphs that show changes over time for:
 - queue length and average queue time for continuing care patients in acute care beds and in community
 - per cent ALC bed days in acute care
 - total demand over time
 - total capacity over time
- Develop a process for each zone to follow that uses data on demand and capacity to understand intermediate-range forecasts for continuing care living options and to have contingency options available to adjust for unforeseen changes in demand and/or capacity.
- Develop education and training for decision-makers on how to use demand and capacity data to maximize the use of standardized reports to influence decision-making.

Recommendation 4

Alberta Health Services engage independent modeling experts to review the current approaches that are being used to predict medium- to long-term demand and capacity in continuing care throughout the province.

Required actions

- Engage operations management experts to advise on the use and implementation of tools such as queuing analysis, discrete event simulation, or system dynamics modeling.
- Engage with experts in geographical information systems to determine the optimal approach for developing geographic specific models so as to best serve the unique needs of particular populations throughout the province.

- Review whether all relevant factors have been identified and used in the models to predict future continuing care demand (for example predicted increases in the incidence of dementia).
- Develop and validate models using historical data where it is available.
- Make explicit the assumptions that underlie the prediction models and consider testing the predictions using different assumptions to gain understanding of the limits of the models that are being used.
- Develop capacity predictions that would take into account occupancy rates that are less than 100 per cent in continuing care.

OVERVIEW

Purpose

On June 18, 2013, Alberta Health Services (AHS) requested that the Health Quality Council of Alberta (HQCA) conduct an independent review of the quality and patient safety implications of the AHS policy *Continuing Care Waitlist: First Available Appropriate Living Option (FAALO)*.¹

Background

Since 1993, when the *Single Point of Entry for Long Term Care Services in Alberta – Program Description*² was created, various policies have been in place that describe how patients access continuing care in Alberta. Following the formation of nine health regions in 2003, most regions established a wait list management policy or protocol of some kind, including placement in a first available living option, resulting in different practices across the province. When AHS became an entity in 2008, work began on a province-wide policy for accessing continuing care throughout Alberta, which resulted in the FAALO policy that is the focus of this review.

The FAALO policy was developed as a requirement of the over-arching *Coordinated Access to Publicly Funded Continuing Care Health Services: Directional and Operational Policy*³ to address capacity issues that affect the flow of patients in the healthcare system. The directional policy was created jointly by Alberta Health⁴ and AHS.

According to the policy, if a site identified by a patient as a preferred location has a waitlist, the patient "shall be offered to move to the first available option that is appropriate to meet his/her assessed unmet needs until his/her preferred site or location becomes available".¹

If the patient accepts the offer for the FAALO site, the patient will be transferred to that site which will be "no further than 100 km driving distance from the patient's primary preferred site or location" and placed on a wait list for his or her preferred site(s).¹ A companion policy, *Continuing Care Waitlist: Prioritization*, ensures that patients who have agreed to a first available space will have priority for moving into one of their identified preferred locations when a space does become available.⁴

In June 2013, AHS withdrew the policy and initiated an internal policy review. AHS also requested the HQCA conduct an independent review of the quality and safety implications of the FAALO policy.

¹ Throughout the document the Ministry of Health is referred to as Alberta Health which includes its previous name Alberta Health and Wellness.

Objective

To meet the Terms of Reference for this review, as shown in Appendix I and II, the HQCA conducted a review and made recommendations on the quality and safety implications of the AHS *Continuing Care Waitlist: First Available Appropriate Living Option* policy.¹ The process of the review included but was not limited to:

- FAALO policies in the legacy health regions in Alberta
- Current but not operational AHS FAALO policy
- Similar FAALO policies in Canada and elsewhere
- Client experiences with FAALO policies in Alberta
- Impact of FAALO policies on the performance of the continuing care system and the broader Alberta health system

Based on the findings and analysis of the investigation, the HQCA developed recommendations and required actions for system-level improvements related to the AHS policy *Continuing Care Waitlist: First Available Appropriate Living Option*.¹

Review team

The review was conducted by the HQCA's Quality Assurance Committee (QAC) in accordance with section 9 of the *Alberta Evidence Act*.⁵ The review QAC included:

- Arlene Weidner, RN, MSc, CHE, Healthcare Systems Consultant, Review Lead
- Anette Mikkelsen, BSc (Psych), BSc (PT), MBA, Quality and Safety Initiatives Lead, Review Administrative Lead, HQCA
- Carmella Duchscherer, RRT, BHS(RT), MPA, Quality and Safety Review Team Lead, HQCA
- W. Ward Flemons, MD, FRCPC, Quality Assurance/Quality Improvement Expert Consultant
- Eric Wasylenko, MD, BSc, MHSc, Health Ethics and End of Life Expert Consultant
- Markus Lahtinen, PhD, Measurement Team Lead, HQCA

The following people provided expert input into the report:

- Rinda LaBranche, RN, BEd, MEd, Patient Safety Lead, HQCA
- Donna MacFarlane, RN, Patient Safety Lead, HQCA
- Amanda Hill, MB, BCh, FRCPC, Clinical Assistant Professor, Division of Geriatric Medicine, University of British Columbia and Geriatric Consultant, Geriatric Medicine, Vancouver General Hospital
- Charlene McBrien-Morrison, RT (CSLT), MBA, Executive Director, HQCA
- Jody Pow, BA, MA, Data Manager Primary Healthcare Measurement Lead, HQCA
- Diane Bischak, PhD, Associate Professor, Operations Management and Leadership Researcher, Canadian Centre for Advanced Leadership in Business, Haskayne School of Business, University of Calgary
- Christiane Langtry, Administrative Assistant, HQCA

Methodology

A mixed methods approach was used to gather information to meet the review objective. Information was gathered from a number of sources:

- **Environmental scan** of other Canadian provinces and territories and their approach to continuing care placement.
- **Documentation review** included those provided by interviewees as well as other documents acquired through Internet searches.
- **A review of the literature** on the topic of continuing care wait list management and the impact of continuing care placement on individuals.
- **Semi-structured interviews with key informants and experts** across the health system to discuss the evolution of and challenges with the FAALO policy.
- **Semi-structured interviews with a purposive sample of residents (or family members)** currently residing in continuing care and placed initially in one of their preferred options or were required to take the first available appropriate living option.
- **Review of current AHS data and performance indicators** for continuing care wait list management (capacity and demand).
- **An expert in operations management research** was consulted.

INTRODUCTION TO CONTINUING CARE WAIT LIST MANAGEMENT

Canada Health Act

The *Canada Health Act*⁶ distinguishes between insured health services and extended health services. Insured health services must be fully insured by provincial healthcare insurance plans. Extended health services include intermediate care in nursing homes, adult residential care service, home care services, and ambulatory healthcare services. These services can be charged for at either partial or full private rates.

Both the *Canada Health Act*⁶ and the *Alberta Hospitals Act*⁷ allow for patients to be charged for receiving hospital care if such care is no longer medically required. In Alberta, patients waiting in acute care for a continuing care living option may be charged for at least the continuing care accommodation rate which is currently set at \$48.15 per day.⁸ This was a feature of many of the Alberta legacy health regions' policies (i.e., policies that were created and used by the former health regions in Alberta). Under the AHS FAALO policy, if patients refuse an appropriate living option, they can be charged \$100.00 per day for occupying an acute care bed.¹ This amount is substantially less than the standard fees charged to 'non-entitled persons' under the Hospitals Act regulations.⁹

A Canada-wide perspective on patients requiring an alternate level of care

To provide a broader context for the use of the first available appropriate living option (FAALO) policy it is helpful to explore how other provinces and territories across Canada have attempted to address the wait list of patients identified as needing an alternate level of care (ALC). These are patients in acute care hospitals, who no longer need acute services, and who are waiting to be discharged to an alternative setting more appropriate to their needs.^{10(p 1)} The Canadian Institute for Health Information (CIHI) identified that ALC patients accounted for 14 per cent of hospital days in acute care facilities across Canada. This equates to almost 5,200 acute care beds occupied by ALC patients on any given day. Of the provinces included in the analysis the highest rates are reported in Ontario and Newfoundland and Labrador.¹⁰

"Like the overall acute care population, ALC patients are a diverse group. However, there are some key ways in which ALC patients are distinct from other patients. In previous work done to profile ALC patients, several groups were identified for targeted efforts to reduce ALC days. These include frail elderly, those with cognitive/behavioural problems and neurology/stroke patients". CIHI analyses support this work and found that these three groups account for a significant proportion of ALC patients.¹⁰ In 2012, CIHI reported that more than half (54%) of seniors [65 years and older] who were identified as having ALC days in acute care were discharged to a residential care facility.^{11(p 1)}

Given the considerable number of ALC patients across Canada, some authors stress the importance of recognizing that "although there has been much discussion about the 'ALC challenge', less attention has been paid to the needs and experiences of ALC patients".^{12(p 34)} Chappell and Hollander emphasize that "the growing numbers of ALC patients in hospital is a symptom of the underlying problem, which is the inadequate capacity to deal with older adults with identified care needs".¹³

Provincial approaches to alternate level of care patients

An environmental scan (Appendix III) was conducted to gain a better understanding of current practice in other provinces for managing continuing care wait lists and policies similar to Alberta's FAALO policy. The scan found nine provinces have developed policies similar to Alberta's FAALO policy that request or require ALC patients to take the first available appropriate living option (in most provinces this is referred to as 'first available bed') to minimize the patient's stay in an acute care setting and to move patients to an appropriate level of care.

Based on its *Long-Term Care Homes Act*¹⁴, Ontario allows patients to remain in hospital while waiting for their preferred option, which supports the consent and choice of the patient. In Ontario, legislation indicates that patients cannot be required to choose a specific number of LTC choices, and cannot be required to accept a first available bed that is not a preferred choice.¹⁵

In 2010 the Ontario Ministry of Health & Long Term Care initiated a project, Access to Care, in which they surveyed all Ontario hospitals to identify characteristics of patients designated as ALC for greater than 40 days. The Toronto Central Local Health Integration Network (LHIN) reviewed their local data and published The Long Stay Alternate Level of Care (ALC) Review & Intensive Case Management Project in the Toronto Central LHIN Final Report, in which they identified that a major contributing factor to the long stays of ALC patients was the lack of an effective 'pull strategy'. They concluded that a proactive strategy was required to transfer those patients to the appropriate place of care as early as possible, and timely transition could occur if the following actions were in place:

- Intervene early in the patient's hospital stay.
- Ensure that the right place of care is selected [it was noted that 35% of patients in their study had inappropriate ALC designations].
- Having designated people accountable and responsible for transitioning the patient.

The report also identified numerous policy and practice issues which included:

- The current *Long-Term Care Homes Act*¹⁴ and Regulations can contribute to ALC days since patients are able to wait in ALC beds for the LTCH home of their choice.
- Long term institutionalization of some patients has resulted in unwillingness by the patient and/or family to relocate to a more appropriate level of care.^{16(p 2-4)}

In May 2012, the Ontario Hospital Association and the Ontario Association of Community Care Access Centres held an invitational roundtable discussion in relation to "what can be done to improve LTC placement practices within the existing regulatory environment...".^{17(p 2)} The participants concluded that there was "little support at the Roundtable for enforcing a "first available bed policy". However, there was strong consensus that patients need to wait "somewhere other than hospital" for their first choice."^{17(p 4)} Although they did not identify a specific policy that would address the transition process, participants did list elements that an LTC Discharge Placement Policy would need to include.^{17(p 4)}

In a review of the effect of the ALC population in Ontario on that province's healthcare system overall, Walker concluded that the "pattern of care for a large cohort of the population is inadequate and inappropriate...(and) a duty exists to transform our healthcare system to meet the needs of this increasingly aged population who will live longer, in states of both health and illness".¹⁸

In the Northwest Territories, the government has indicated that a FAALO policy is not required at this point as most people accept the long-term care bed offered.

All the FAALO-like policies that were reviewed asked patients, depending on the province or territory, to identify between one and five preferred continuing care sites. All of these policies offered patients an opportunity to transfer to a facility of their choice when space became available.

Alberta, Saskatchewan, New Brunswick, and Nova Scotia identified that the first available location was required to be within a specified driving distance restriction. Geographic restrictions applied to several rural areas of Newfoundland's Eastern Health region. While five of the health regions in Saskatchewan have no distance limits, the Saskatoon Health Region has a distance limit of 75 kilometres, and the Regina Qu'Appelle Health Region is considering a 150-kilometre distance limit. British Columbia included criteria that the offer of a first available bed needed to consider the location of family. Ontario and Newfoundland and Labrador identified specific criteria under which a bed may also be offered to a spouse.

Since the release of the February 2012 Ombudsperson's report in British Columbia, some health authorities in that province are giving more consideration to the appropriateness of the bed being offered, and are taking into account such factors as the distance from the person's family and friends, location of a spouse in another facility, and suitability from a clinical perspective. The 2010 consultation paper by the Law Reform Commission of Saskatchewan, *Civil Rights in Saskatchewan Long-term Care Facilities*, identified a concern about the lack of respect in the placement process as the first available bed policy was causing additional stress to the family.¹⁹

Waiting in acute care

Hospitalization of many older patients results in functional decline and development of new functional deficits.^{20,21,22} This decline leads to "increased risk of illness and death, often irreversibly diminishes quality of life, results in less autonomy and greater dependence".²² As Walker points out, "the acute care hospital is not designed to meet a patient's restorative, supportive or rehabilitative needs, but has conversely been shown to advance functional deterioration and place patients at significant risk of hospital-related infections, falls, and other adverse events".^{18(p 6)} While hospital care redesign to better address the needs of the elderly has been proposed, "much remains to be done to improve conditions for seniors".²³

A review of documents identified a consistent theme associated with conflicting patient needs; that is, the health risks to clients when they are kept in hospital waiting for a space, and the additional stress placed on patients when they are asked to temporarily move to a less desirable space, such as a three-bed room. It was further identified that the inconvenience and stress for the patient and family is outweighed by the risk to their health and quality of life should they remain in acute care where they are exposed to infection and other health hazards. This is a consistent driver in the attempt to move people from that setting in as timely a manner as possible.

Some authors view this phenomenon from more of a system perspective, focusing on why so many people are waiting in hospital and the shortage of continuing care capacity, rather than appearing to blame or put the onus on the ALC population. "However, it is generally acknowledged that ALC patients are not the cause of patient flow inefficiencies within the healthcare system. Rather, the growing

number of ALC patients reflects a failure of the healthcare system to meet the needs of older adults with complex and declining health".^{12(p 34)}

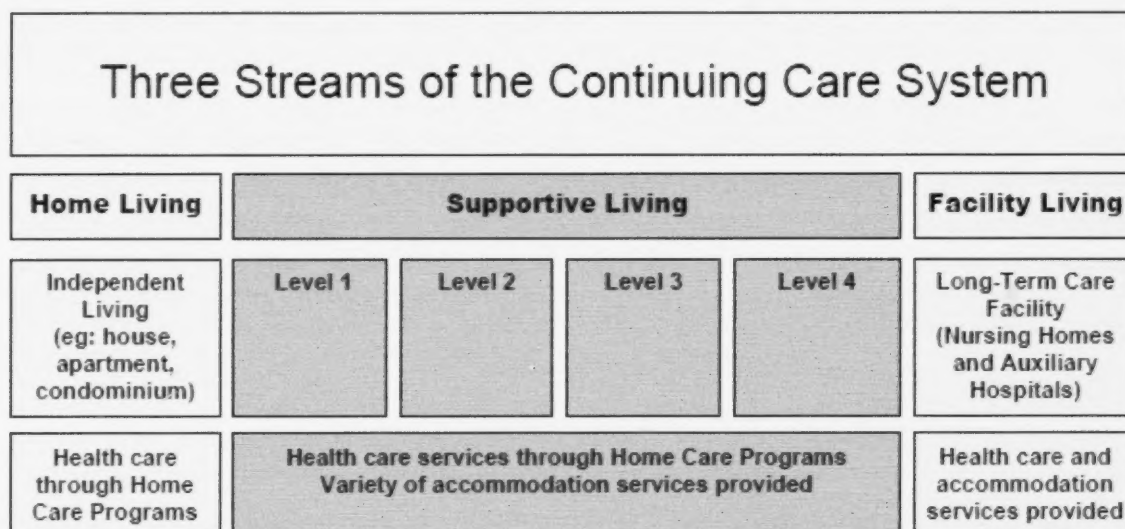
The use of acute care beds by patients who no longer require acute care services contributes to the shortage of acute care capacity, thus reducing the bed availability for emergency department (ED) admissions and elective surgeries.²⁴ Trying to care for patients in the emergency department who need inpatient care is also inappropriate, and there is evidence that delayed admission of these patients to the appropriate inpatient setting is detrimental to their prognosis.²⁵ Hence, the capacity of the continuing care component of the healthcare system impacts capacity in the acute care system.

FINDINGS

Continuing care in Alberta

The healthcare system has several subsystems such as acute or hospital care, public health and population health, primary care, and continuing care. Alberta Health Services (AHS) defines continuing care as an "integrated range of services supporting the health and well-being of individuals living in their own home, a supportive living or long-term care setting. Continuing care clients are not defined by age, diagnosis or the length of time they may require service, but by their need for care."³ This includes home care services, supportive living levels one through four, and long-term care as identified in Figure 1.

Figure 1: Three Streams of the Continuing Care System²⁶



As one interviewee commented, continuing care could be reconceptualized to 'living options with care added'. The fundamental challenge is that for this population, there is the dual need for a place to live and for healthcare or assistance with activities of daily life. This concept, of combining healthcare needs with different living or housing options, is fundamental to understanding the levels of service provided in continuing care.

Coordinating access to continuing care: a single point of entry – 1988

The FAALO policy and the concept of co-ordinated access (or a single point of entry) originated about 25 years ago as an important feature of equitable access to continuing care for all Albertans (Appendix VI). "The need for a co-ordinated assessment and admission process to streamline entry to long-term care services in Alberta was identified in the early 1980's".² A model for single entry assessment and placement was developed in 1984 by the Inter-Departmental Committee on Long Term Care. The model was tested in rural and urban settings and culminated in the release of *A New Vision for Long Term Care – Meeting the Need* in February 1988²⁷. Implementation of a single point of entry for long-term care services in Alberta began in 1993.²

A core element of the placement process included wait list management, which described how to prioritize patients on a wait list for admission to a continuing care space. In that early iteration, first priority for admission was given to people needing urgent admission from the community to prevent an unnecessary admission to hospital. Urgent meant there had been a significant breakdown in the informal support system or change in the individual's functional ability, and the individual's needs exceeded the available resources of the home care program and other community services. A caveat to this priority placement was that "the individual had to be willing to accept the first available bed in the region, and the individual requires and agrees to accept care in a facility immediately."²

Other factors that were to be considered in determining an appropriate placement for someone included assessed needs, choice of facility, family situation, and the distance of the facility from the individual's community.

Healthy aging: new directions for care (Broda Report) – 1999

The continuing care system in Alberta has been undergoing significant change since the release of *Healthy Aging: New Directions for Care* in November 1999. Often referred to as the 'Broda Report', it advocated for greater use of supportive and home living options to better serve the differing needs of an aging population, rather than continuing to emphasize the predominant model of the long-term care centre (auxiliary hospitals and nursing homes).²⁸

The policy advisory committee created a model of a home living stream, supportive living stream, and facility living stream. Home was seen as the first choice, and, as described in the report, "people will have the support they need so they can remain independent as long as possible. Home care services will be increased dramatically." "Supportive housing will expand and people will have many different options for the kinds of services available" and "the focus will be on bringing services to the people, not bringing people to services." Continuing care centres (facility living) were only to be accessed when a person's needs could not be met in either of the other options; this would apply primarily to those with complex and chronic health needs.^{28(p 17-18)}

With other options in place, the committee urged "caution in 'over-building' long-term care facilities if people's needs can better be met in other, more appropriate and less costly alternatives". The report suggested the first priority should be to "expand home care services" and to increase these services in supportive housing arrangements (a priority strategy that continues today within AHS, along with the focus on increasing capacity in supportive living spaces rather than facility living). The report also identified the reality of a "backlog of people who need to be cared for in LTC [long-term care] centres (projected to be an additional 600 beds over the next 3 years)" and the need to find more appropriate spaces for these people, which would free up acute care beds in hospitals for those who need them. The report highlighted the fact that "acute care beds are not an appropriate environment for people with long term healthcare needs".^{28(p 23)}

Consumer choice was also a key principle in that 1999 report, as evidenced by the following quote: "The direction will be very different from today. It will reflect a fundamental shift, putting the needs of the individual first and giving people choices in where and how their assessed needs are met."^{28(p 15)}

The report underscored that "Each person must be treated as a person and not as a bed. We would not accept school systems speaking of the number of chairs they are teaching."^{28(p 26)}

One of the report's recommendations was to "introduce a new co-ordinated access process to assess needs and ensure appropriate referrals to the full range of continuing care services, whether those are provided at home, in supportive living arrangements, or in continuing care centres."^{28(p 28)} This recommendation provided further support for the coordinated access approach to continuing care services implemented by Alberta Health in 1993 and for the concept of keeping people in their homes as long as possible. While the report did not specifically address issues of wait list management for continuing care spaces, the report did acknowledge the "backlog of needs"^{28(p 28)} and recommended a range of actions to "take the pressure off continuing care facilities and acute care hospitals".^{28(p 29)}

Task force on continuing care health service and accommodation standards – 2005

In 2005, a Task Force on Continuing Care Health Service and Accommodation Standards was struck by the Honourable Iris Evans, then Minister of Alberta Health and Wellness, and the Honourable Yvonne Fritz, Minister of Alberta Seniors and Community Supports, with the "goal of restoring public confidence in continuing care health services and accommodation in Alberta". The task force's report, *Achieving Excellence in Continuing Care: Final Report of the MLA Task Force on Continuing Care Health Service and Accommodation Standards*, summarized input received from stakeholder groups and Albertans through public meetings, verbal and written presentations, and discussion guides.²⁹

Task force members heard that finding and obtaining the right combination of healthcare and housing services was difficult and that, with few exceptions, people should be able to receive the services they need in their preferred place of residence. They also learned that couples were being separated because of different needs for care, there was regional variation in prioritizing individuals on wait lists, and one of the disadvantages of the first available bed policy was that people were placed in settings that were not the most appropriate to their needs or preferences.

One of the recommendations of the task force was to "review and modify the policies related to accessing long-term care, including:

1. The development of alternatives to 'first available bed' placement including not reassigning the priority for those who do not take the first available bed, and
2. Better support for individuals and families who would like to make an inter-regional transfer when waiting for, or already living in, long-term care."²⁹

Continuing care strategy: aging in the right place – 2008

In 2008, Alberta Health released *Continuing Care Strategy: Aging in the Right Place*, which is the current government policy direction to move toward a "more client-focused continuing care system that puts health and personal care needs first and promotes increased choice of where to receive those services".^{30(p 3)} This report places an emphasis on supporting seniors and individuals with disabilities to remain in their own homes and communities rather than be admitted to a supportive living or long-term care facility. The strategy identified that the number of long-term care spaces would be held constant for several years at approximately 14,500.^{30(p 12)} By 2011, 1,225 supportive living spaces would be added and by 2015 half of all current long-term care spaces would be refurbished or replaced.^{30(p 13)}

The situation in which certain sites often have vacant spaces (and therefore often become the first available living option) is perceived by some interviewees to be because of their physical structure, in a less desirable location, and/or provides a more institutional approach to care. They often become the temporary destination for a patient waiting for one of his or her preferred options, which could lead to

high turnover. For example, one site indicated they had 30 admissions and discharges in a month which was more than their usual activity.

Provincial service optimization review – 2008

A decade after the Broda Report, the *Provincial Service Optimization Review* noted that all regions had been somewhat successful in reducing reliance on LTC spaces, though “significant regional variation still exists in the use of LTC and that unmet demand is high”.^{31(p 14)} The former Chinook Health Region was noted as “most aggressive in reducing LTC usage”.^{31(p 14)} In the early years of regionalization, the Chinook Health Region made a concerted effort to create different levels of continuing care capacity to better match the needs of its population, including converting some acute care beds to continuing care.

Reliance on the LTC stream has “implications for both the system’s access and its cost-effectiveness”.^{31(p 14)} Long-term care spaces, which are designed to serve patients with complex medical needs, is significantly more expensive than supportive living spaces.^{31(p 14)} In addition, items such as medications and medical supplies are provided without charge to residents in long-term care, which is not the case in supportive living. At the time of this particular provincial review (2008), 11 per cent of Alberta hospital patients were waiting for LTC or supportive living placement. It was projected that “transitioning the entire province to Chinook’s current mix of LTC and supportive living could reduce Alberta’s need for LTC beds by 20% resulting in roughly \$60 million in annual operating savings”.^{31(p 15)} The review highlighted that “it will be important for Alberta to take a systematic approach to determining the most appropriate mix to target”.^{31(p 15)}

The shift from facility living (LTC) to supportive and home living was intended to keep patients closer to home and improve their experience(s). The report affirmed the need to reduce barriers to using these types of care, and to “conduct analyses on an expedited time frame to determine what level of LTC facility investment is optimal”.^{31(p 5)}

The report encouraged the use of best practices for patient assessment and the placement process. It went on to state, “Current continuing-care data collection systems do not uniformly collect patient assessment, occupancy, bed supply, or cost information. Better data collection would be required if Alberta wanted to determine the appropriate mix of LTC, supportive living, and home care, as well as to assess progress and manage performance”.^{31(p 16)}

Right care in the right place – 2010

Building on the goals from the *Continuing Care Strategy: Aging in the Right Place*, AHS developed a continuing care strategy that would improve the care of seniors requiring ongoing support either through home care or within supportive living environments.

The strategy identified a shortage of spaces for patients waiting in acute care and in the community for supportive living and long-term care. The number of ALC days in hospital further emphasized that people were not in the right setting for the care they needed, resulting in an inefficient use of acute care resources. The response to this problem was to increase the number of continuing care spaces to meet the needs of an aging population.

The document also recognized the importance of supporting independence through choice. This would be achieved by providing a range of services (home care, supportive living, and long-term care) within reasonable distances so that people could stay connected to families and community supports. Seniors would also be supported as they age in place with the least possible number of moves.

Ministerial Directives – 2012

In February 2012, the Alberta Minister of Health issued three directives to AHS targeted towards decreasing acute care hospital occupancy and reducing wait times in Alberta. One directive focused specifically on ALC patients requiring AHS to reduce by half the number of patients assessed and waiting in acute and sub-acute facilities for continuing care from January 31, 2012 baseline. In reporting their progress, AHS identified actions beyond adding continuing care capacity to reduce both admissions to acute care for selected populations and ALC days. These actions included implementation of 'Integrated Home Health' (a program providing higher intensity of integrated community and home care services including home care and services through a primary care network or family care clinic), 'Path to Home' (a program to proactively manage discharge and transition of patients to an appropriate level of care) in addition to initiatives such as providing additional community care services as an alternative to facility-based care and optimizing transitions and continuing care decisions. In the summary progress report AHS indicated that 'substantial progress' has been made in continuing care.³²

Alberta Health Services Health Plan and Business Plan 2013-2016

In 2012, AHS examined the ideal health service settings for people assessed and waiting for placement, based on the living option guidelines. The results showed 41 per cent of individuals currently waiting in acute care for a continuing care living option would be best served in a long-term care facility; and 58 per cent would manage best in a supportive living facility. Of those waiting in the community for a continuing care living option, 15 per cent would be best served in LTC and 83 per cent in supportive living environments.³³

Some interviewees suggested the commitment to building the necessary continuing care capacity has not kept pace with the needs. One interviewee commented that during the mid-2000s, the planned capacity expansion was thwarted when the costs of construction rose, resulting in a financial disincentive to build.

In those communities where there is an oversupply of facility living spaces, people may be placed into those sites even though their assessment indicates that the most appropriate placement would be supportive living.

The differences in cost to the resident between facility and supportive living, make it "almost impossible to get those individuals to move" when an appropriate living space does become available, as noted by one interviewee. Interviewees identified there is resistance from some advocacy groups in Alberta who do not support the expansion of supportive living options, believing instead that more facility living spaces are required.

The *Alberta Health Services Health Plan and Business Plan 2013-2016* identifies further development of continuing care spaces, options, and capacity as a key action. "Per cent of patients placed in continuing care within 30 days" is identified as a strategic measure with a target to increase to 80 per cent for patients placed from acute/sub-acute care, and 60 per cent for patients placed from the community.³³ Deliverables include an additional 1,000 spaces available in 2013-14. Interviewees were not able to confirm why the acute care and community targets were different. As one interviewee indicated, however, this performance target has become a driver for behaviour, proposing it may have created additional pressure to discharge patients from hospital, perhaps resulting in "unintended consequences". As of January 2014, the performance measure combines hospital and community

admissions to continuing care within 30 days with a single target of 68 per cent for 2014-15 and 70 per cent for 2015-16.³⁴

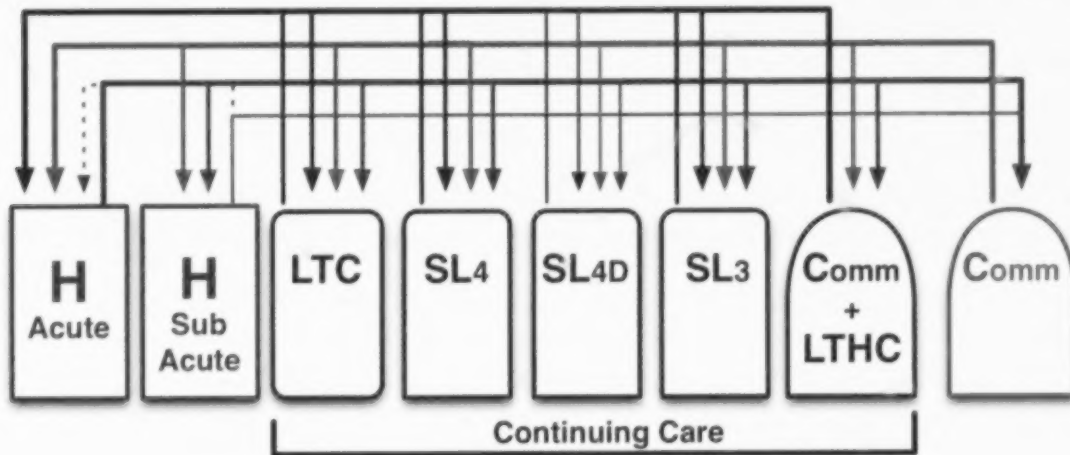
Performance of Alberta's continuing care system

How well Alberta's continuing care system has met the population's needs over the past decade can be only partially evaluated, due to challenges and inconsistencies with data availability and definitions. Evaluation of performance is best done through a quality lens. Using provincial administrative data, obtained from Alberta Health Services' (AHS) Data Integration, Management and Reporting (DIMR) unit, two dimensionsⁱⁱⁱ of the HQCA's Alberta Quality Matrix for Health³⁵ – accessibility and appropriateness – were examined for this section.

Accessibility can be evaluated from two perspectives: how many people are waiting in line (queue length) and how long someone waits in a queue until the required service becomes available (average queue time). People who require continuing care services are either waiting in acute care (hospitals) because they are unable to return home or are waiting in the community. Patients who are already in one type of continuing care may require a higher level of support and so it is possible that demand for certain types of continuing care services may come from within the system itself (e.g., someone who is in an SL-3 facility develops progressive dementia and requires an SL-4D facility). The interdependence of acute care, continuing care, the community, and the different types of services that a patient may require over time is shown in Figure 2.

ⁱⁱⁱ The other four dimensions are acceptability, efficiency, effectiveness, and safety.

Figure 2: Interdependence and possible 'patient flow' between acute care, continuing care, and community*



*H (hospital); LTC (long term care); SL (supportive living); Comm (community); LTHC (long term home care)

When evaluating access to continuing care it is important to consider both major sources of demand, acute care and community, to gain a complete picture of system performance. If, for example, only acute care data were analyzed, and queue length and average queue time were found to be acceptable, one could wrongly conclude that the continuing care system is functioning well, even if community queues were increasing. Historically, the most valid data available at the provincial level has been found in the acute care sector.

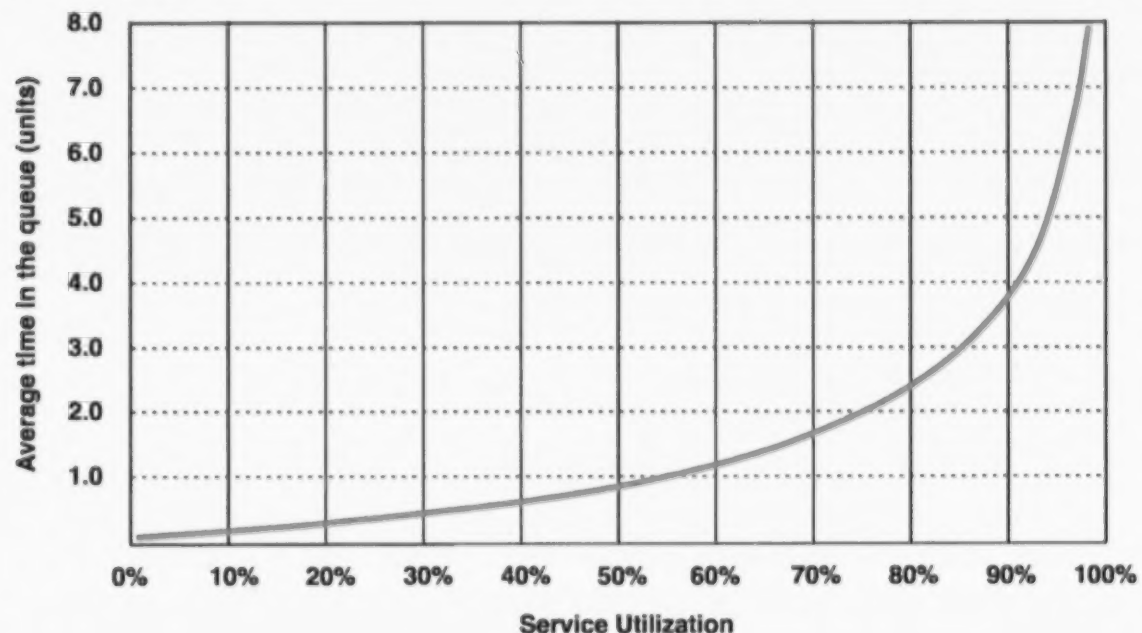
It is important to evaluate the effects of constrained access to continuing care on other parts of the system. In addition to tracking numbers of people in the queue and average queue time, the percentage of patients in acute care beds who are waiting for continuing care (ALC patients) is often calculated. Thus an important measure of patients waiting in acute care for a continuing care space is the number of ALC patients, more commonly reported as per cent ALC. When a substantial number of ALC patients are using acute care resources it means those resources are not available for patients waiting for elective surgery or waiting in the emergency department for admission to hospital.

The science of waiting – operations management and queuing theory

Operations management refers to activities and decisions made for the effective and efficient use of resources. In the case of managing a resource like continuing care it requires an in-depth understanding of the amount of resource that is available (capacity), the amount of demand there is for that resource, the variability in demand and capacity, and how well demand and capacity are matched over time. Understanding these relationships as well as their effect on queue length and queue time are best explained by queuing theory. Queuing theory explains the relationship between the number of spaces and the length of the queue (wait list). In particular, queuing theory demonstrates that the relationship between these two quantities is not linear (proportional). Without queuing theory, there is no easy way to determine what the average wait or the average wait list will be for a given number of spaces.

Queuing theory shows that, all else held equal, as utilization of a system's total capacity moves closer to 100 per cent use (in continuing care this would refer to occupancy), the length of the queue will climb sharply (Figure 3). The exact shape of the curve in Figure 3 depends on many factors but the relationship between average queue length and percent service utilization (occupancy) holds, and it is related to the variability in the timing that people begin waiting for the service and the variability of when there is capacity to provide the service.

Figure 3: Relationship between service utilization and average queue length in a simple service relationship with one source of demand and one service provided (Adapted from the 2012 EDCAP HQCA Report)

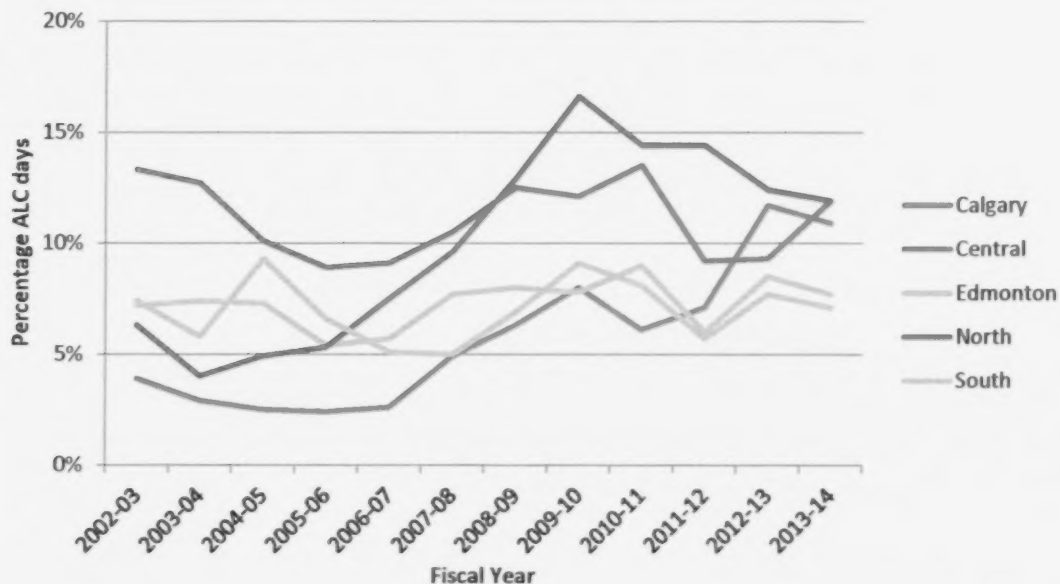


Continuing care system performance – accessibility

Data on accessibility are presented for each of the five AHS zones. Per cent alternate level of care (ALC) days represents the proportion of all the ALC bed days for discharged patients from a specific time period (numerator) compared with all bed days for discharged patients from the same time period (denominator). Figure 4 shows the percentage of ALC days of total hospital days by month from fiscal year 2002 until November 2013 (fiscal year 2013-14). Definitions of ALC were inconsistent across the province for the time reported, meaning some variability between zones may be due to differences in definition rather than true performance. This change in definition mainly affected the Calgary Zone. Changes in data collection after April 2013 have begun to address the data definition inconsistencies, and therefore it is reasonable to compare differences between zones over the past several months only. Prior to that, only changes over time within zones should be considered valid.

The provincial average for ALC days has remained close to 10 per cent over the years presented, with marked increases seen in the Calgary Zone compared with relatively stable percentages in the South and Edmonton zones. The relatively abrupt increase seen in the Calgary Zone in the fiscal year 2011-12 may be due to the recognition of the data definition issue and the work begun to address this inconsistency. Despite large increases in the provincial population, only the Calgary Zone has shown consistent increases in percent ALC days over several years.

Figure 4: ALC days as a per cent of total hospital days by fiscal year for the five Alberta Health Services zones



Another key continuing care system performance measure is the number of patients in the queue (wait list) for a continuing care living option. The numbers for each zone are shown in Figures 5 through 9. The number of patients admitted to a continuing care living option in each zone is also reported; this could be considered representative of the capacity created that month. The number of people admitted demonstrates the actual available placement, and excludes wait list holds and admission delays that can be attributed to the patient. The number represents a snapshot on the last day of the report period, the last day of the month. If the lines mirrored each other, or were overlapping, it would suggest that the number being placed and the number waiting were similar over a period of time.

From April 2010 to November 2013, the South Zone best matched the number of people waiting for a living option (demand) with the number admitted (capacity) (Figure 5). The presented data include patients in acute, sub-acute, and community settings. The Edmonton Zone shows improvement and this appears to have occurred as of April 2013 (Figure 6). In comparison, Calgary has historically shown the largest gap between number waiting and number admitted; improvement was occurring throughout 2012, but worsened again in 2013 (Figure 7). Similar to the Calgary Zone, the Central Zone's gap between demand and capacity was mismatched but started to improve through 2011 and 2012; like Calgary it started worsening in 2013 (Figure 8). The North Zone has shown steady improvement since 2011 (Figure 9).

Figure 5: The number of patients waiting and the number admitted to a continuing care living option, by month and year for the South Zone

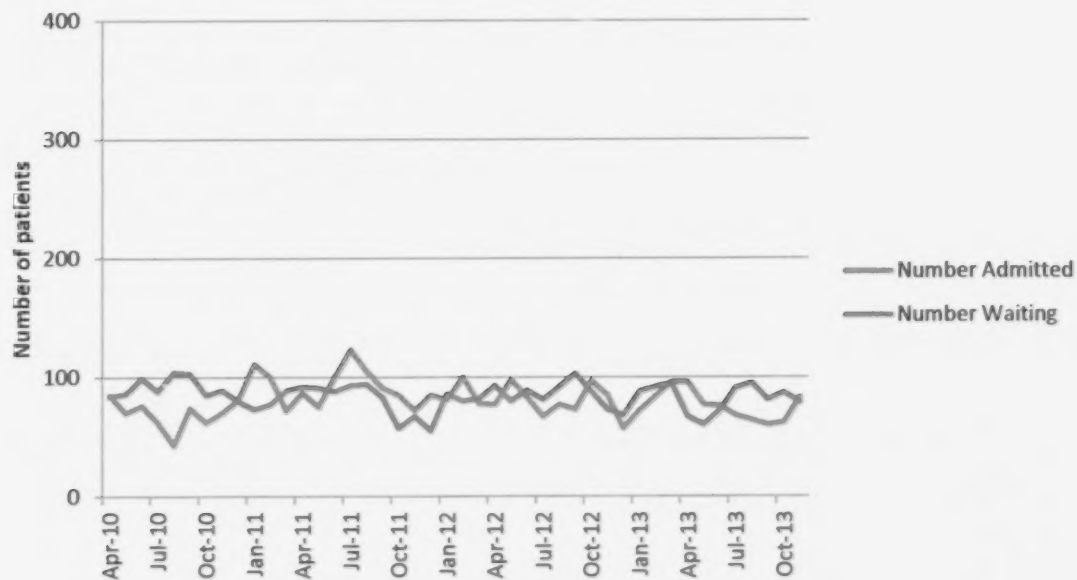


Figure 6: The number of patients waiting and the number admitted to a continuing care living option, by month and year for the Edmonton Zone

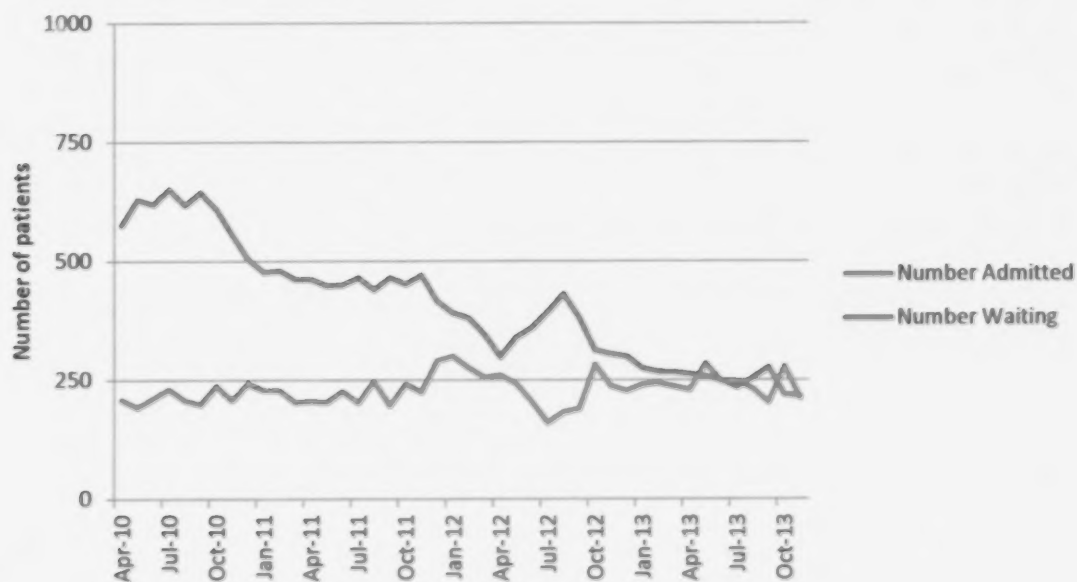


Figure 7: The number of patients waiting and the number admitted to a continuing care living option, by month and year for the Calgary Zone

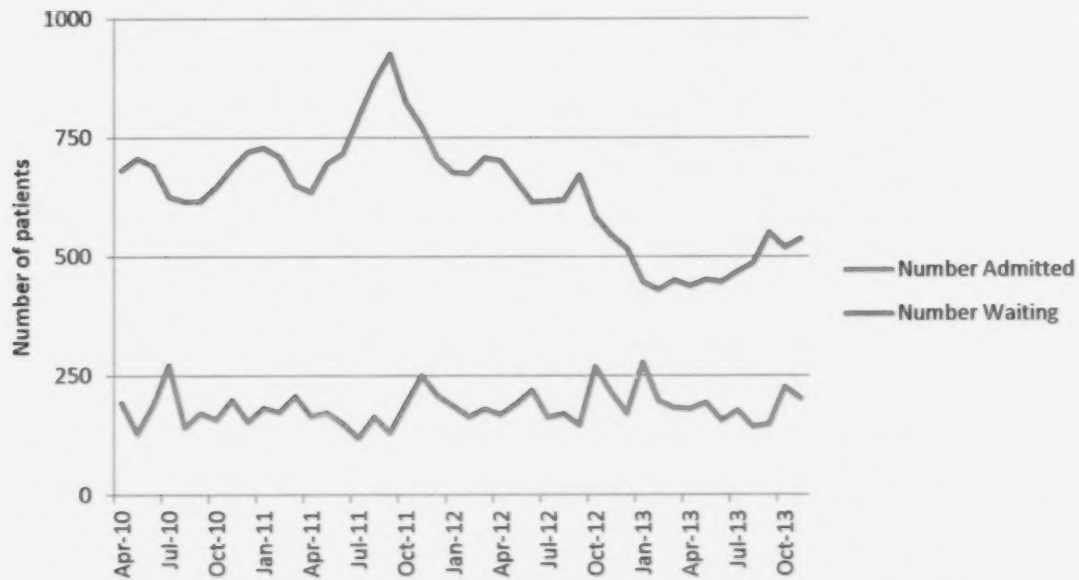


Figure 8: The number of patients waiting and the number admitted to a continuing care living option, by month and year for the Central Zone

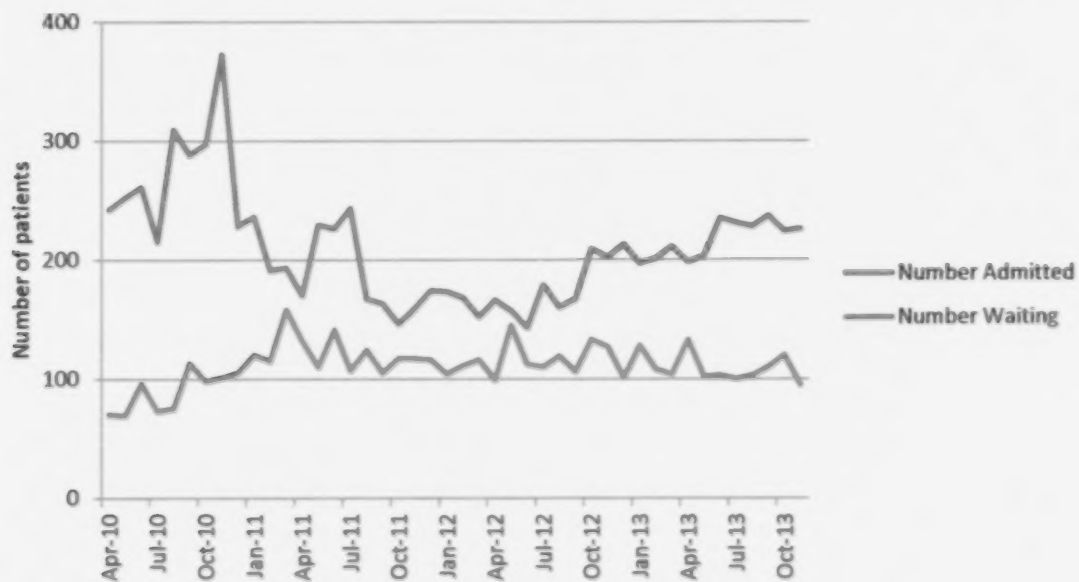
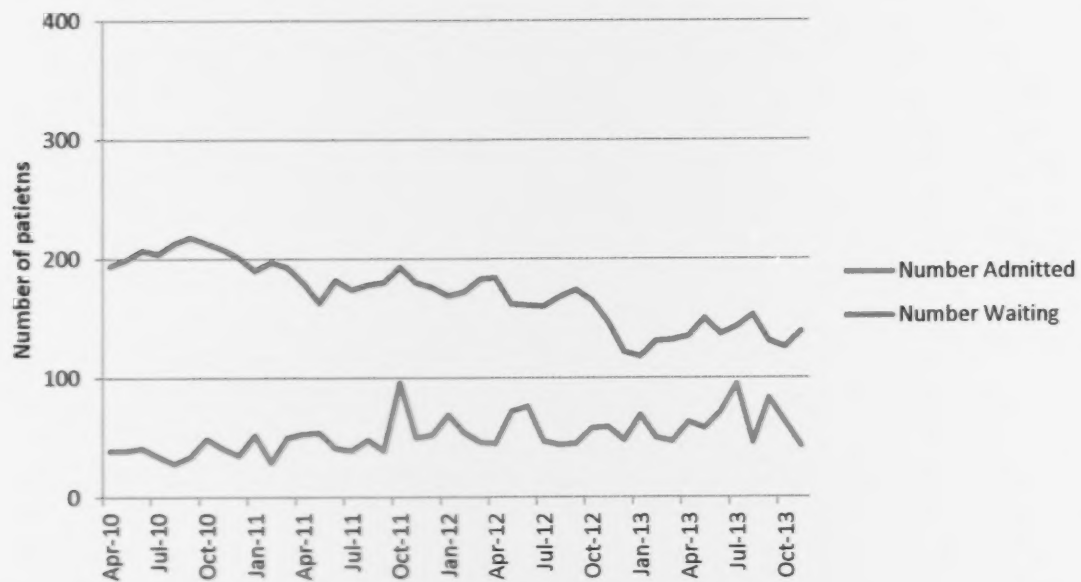


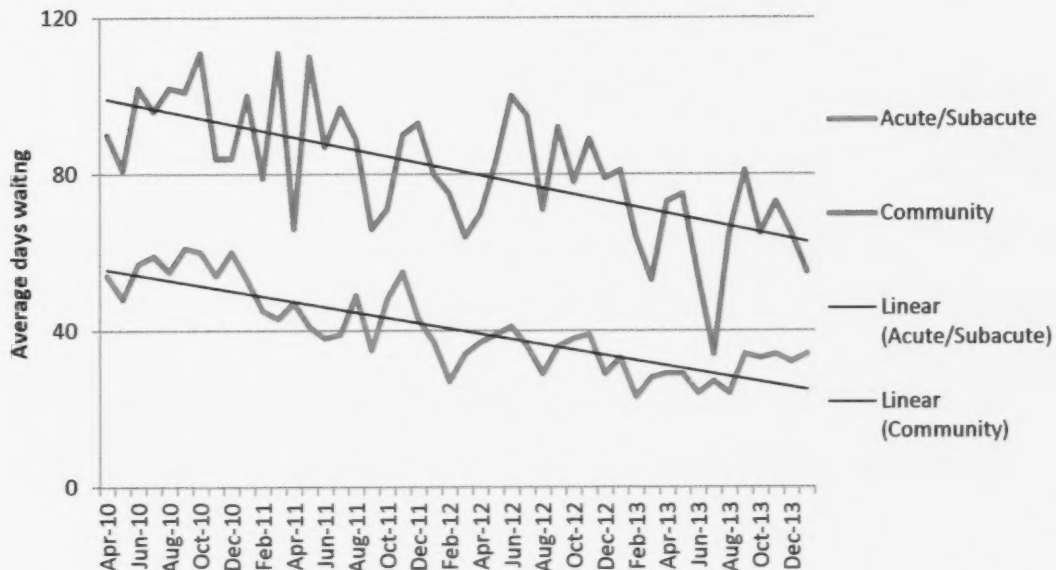
Figure 9: The number of patients waiting and the number admitted to a continuing care living option, by month and year for the North Zone



Average Days Waiting for Placement

Figure 10 displays the average days waiting for a continuing care living option. The graph shows two trend lines, which indicate a decrease in average wait over time for both patients' waiting in acute/subacute and community. However, the trend line is not an indication of an improvement in wait time; it is a descriptive measure of the overall wait time variation. In order to ascertain whether or not there is a discernable improvement, each area (acute/subacute and community) is examined separately.

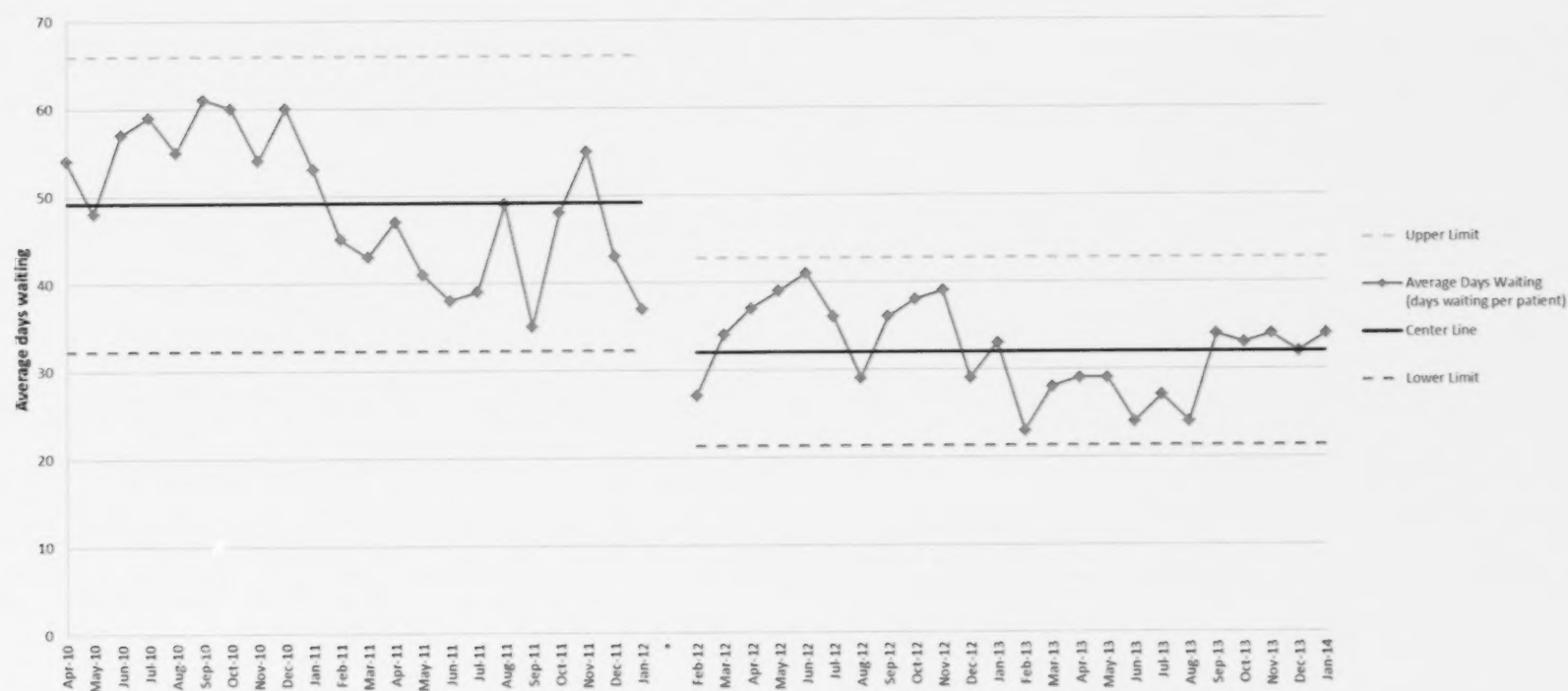
Figure 10. Average days waiting for a continuing care living option by patients' in acute/subacute and community, Alberta



Note: these are wait times for individuals whose last location prior to placement was acute/subacute care or community but can also include time waiting in the other area.

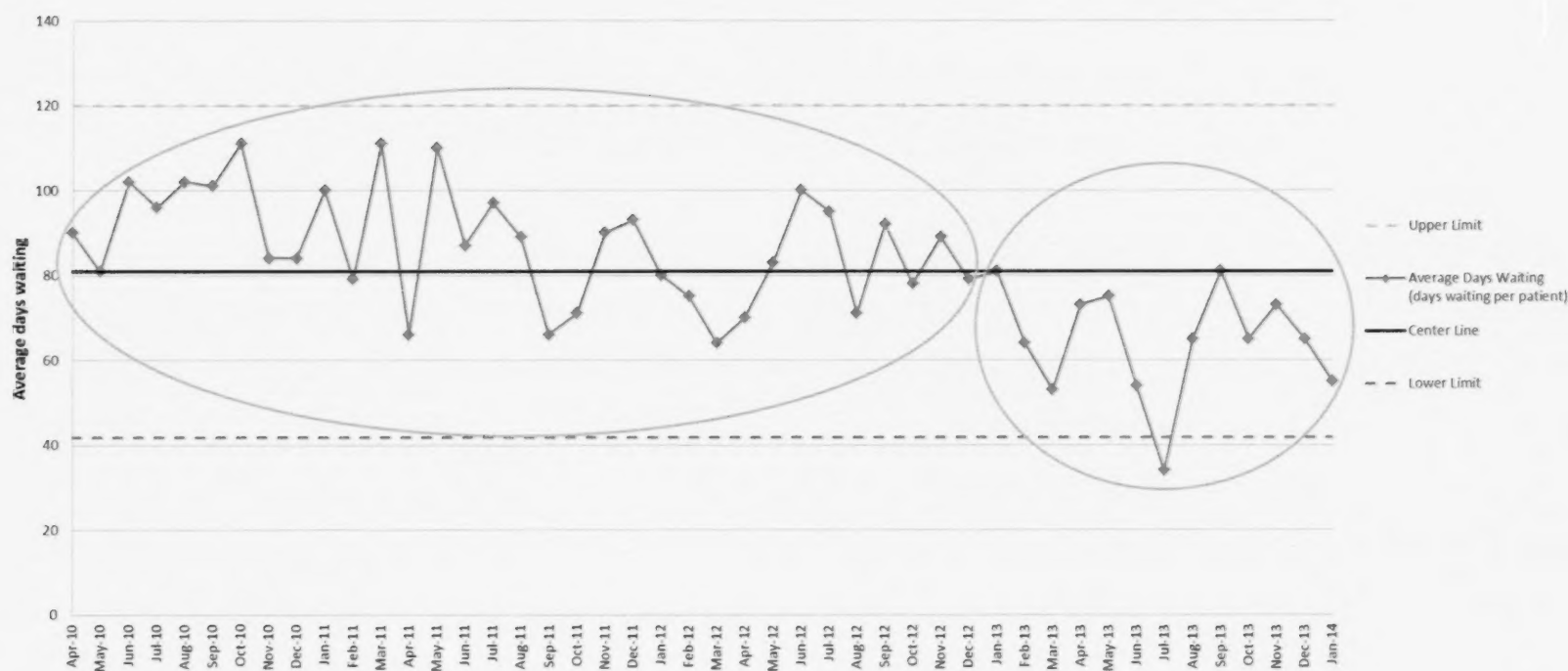
Using statistical process control methods, an examination of patients waiting in acute/subacute indicates two distinct periods. The first period shows a higher average wait time than the second period (see Figure 11). The period from April 2010 to January 2012 represents an average wait time of 49 days. February 2012 to January 2014 represents an average wait time of 32 days; this represents a 35% reduction compared to the first period. In the second period, there are a sufficient number of data points to indicate a distinctly new pattern of performance.

Figure 11. Average days waiting for placement from acute/sub-acute, Alberta



For patients waiting for placement in the community, the data does not currently support an improvement in wait time (see Figure 12). The period from January 2013 to January 2014 is beginning to show a lower than average number of days waiting, with a consistent pattern of data points below the 81 day average. If the pattern continues for another four to six months then it would be reasonable to conclude that there's been an improvement (decrease) in average wait times province wide, however, further analysis is required.

Figure 12. Average days waiting for placement from community, Alberta



Continuing care system performance – appropriateness

Data on patients who were wait listed for continuing care living options for the Calgary, Edmonton, and South zones are presented in Figures 13 to 15. These numbers are calculated on the last day of each month. People are assessed as needing continuing care according to the *AHS Admission Guidelines for Publically Funded Continuing Care Living Options* and then wait listed according to current available and appropriate continuing care living options. The difference between the actual living option that people are wait listed for (LTC, SL4, SL4-D, or SL-3) and the optimal living option that they require (according to the Living Option guidelines) is shown in these figures. The closer the lines are to zero the better the match between optimal assessed need (i.e., the most appropriate living option based on needs) and actual availability. In the Calgary, Edmonton, and South zones, more patients were wait listed for LTC spaces than the number who required them because there were more LTC spaces than supportive living options (SL-4 and SL-3). This has begun to improve over the past two to three years, but in interviews it was noted that some patients will still be inappropriately placed into LTC if that is the only capacity that is available. Data are shown for patients waiting in the community; similar trends are seen for patients waiting in acute and sub-acute care, although the absolute differences are not as great. Data from the Central Zone are similar to the South Zone; data from the North Zone are similar to the Edmonton Zone.

Figure 13: Difference in actual minus optimal wait list numbers for community patients in the Calgary Zone

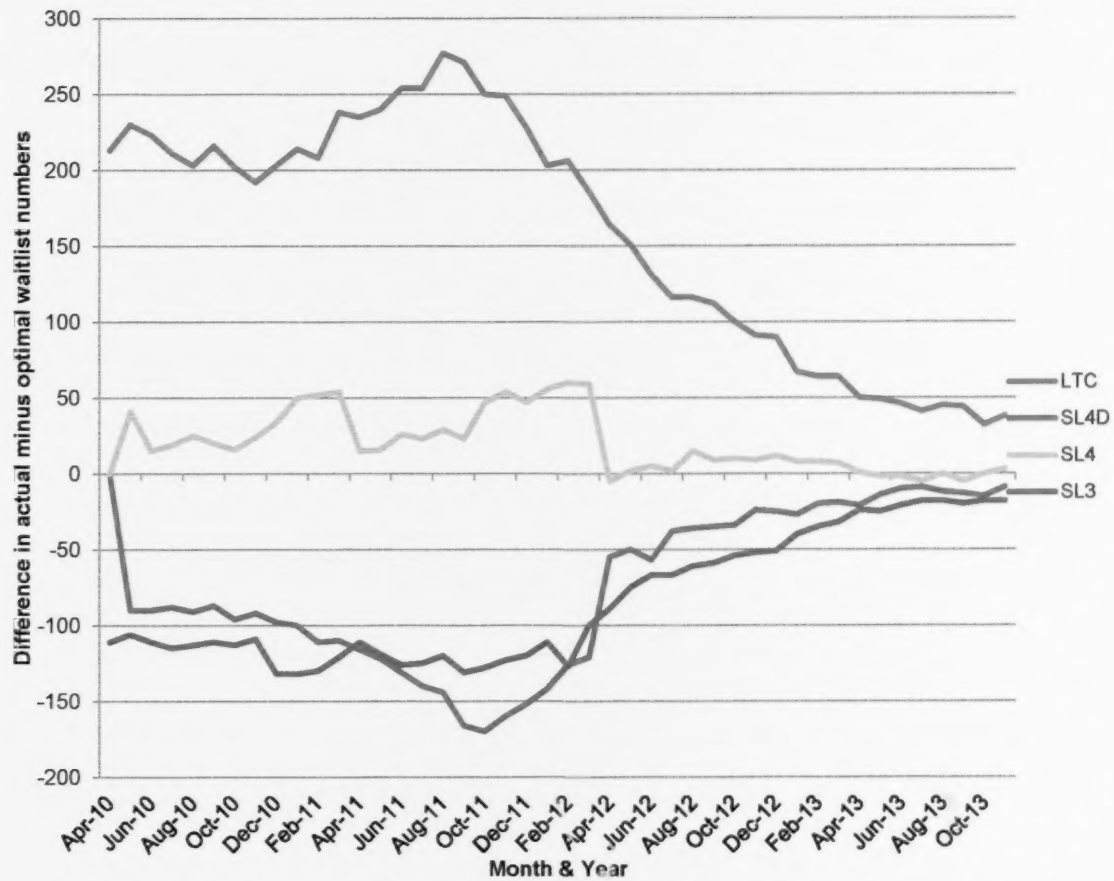


Figure 14: Difference in actual minus optimal wait list numbers for community patients in the Edmonton Zone

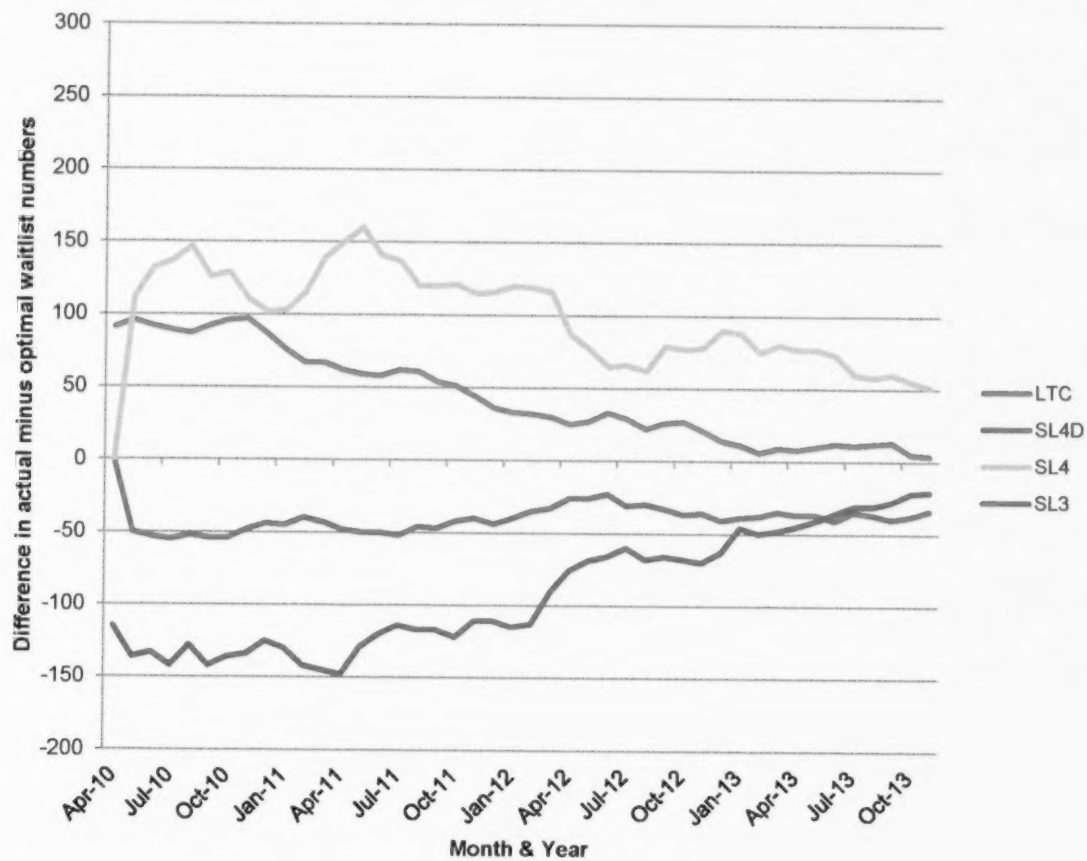
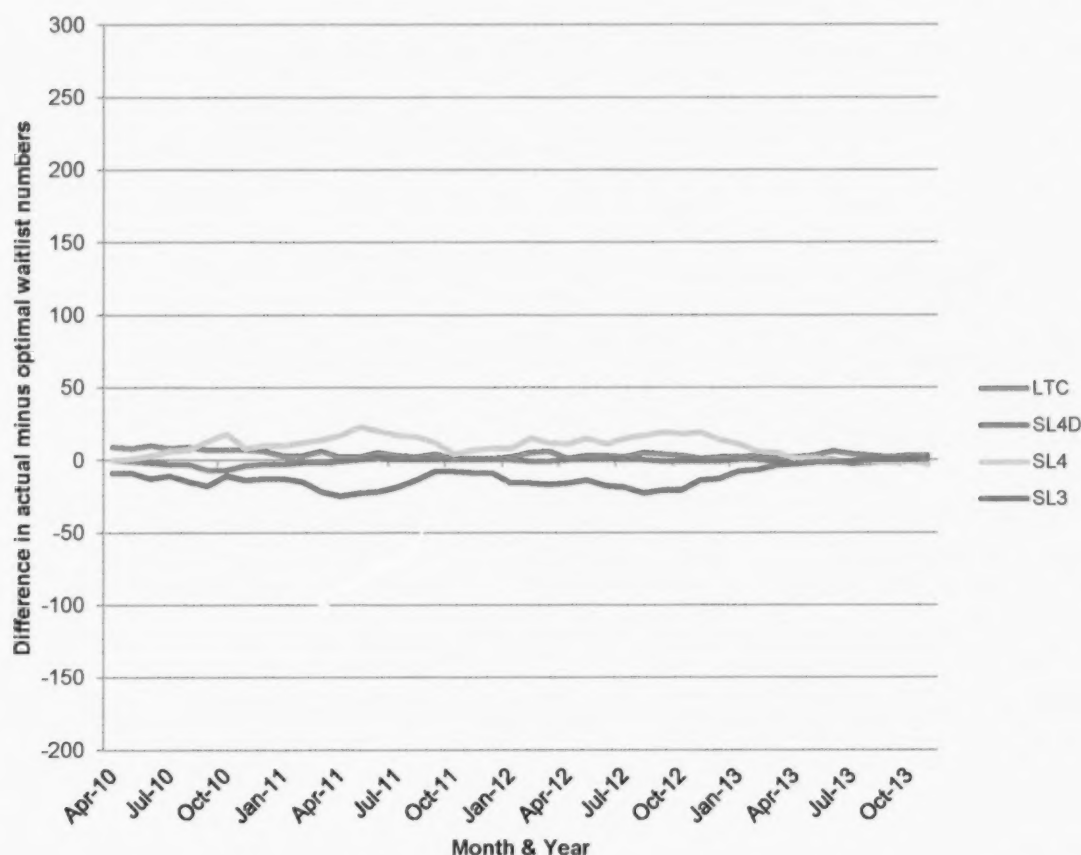


Figure 15: Difference in actual minus optimal wait list numbers for community patients in the South Zone



As these figures show, the Calgary Zone, until recently, had the greatest differences between actual and optimal wait list numbers. The success of the former Chinook Health Region's efforts at planning continuing care and acute care needs for its population likely accounts for the smaller differences seen in the performance of the South Zone.

Planning for the future of Alberta's continuing care system

The data shown in Figures 5 to 15 clearly show historical problems with accessibility and appropriateness in the continuing care system that are either related to inadequate forecasting or the inability to deliver on a planned number of spaces. It is critical that the forecasting be as robust as possible in estimating the need for continuing care living options to avoid repercussions to other parts of the healthcare system and to individual Albertans.

Predicting the future is difficult. However, well-established methods, taken from the science of operations management, can increase the usefulness of prediction models. Several concepts are important to consider when modeling (for forecasting) a system like continuing care:

1. There are a number of best practices used in management science for modeling such systems. The science of demand forecasting is well established and can be used to provide estimates of future demand that take into account the inherent demand uncertainty. In addition, there are three types of modeling approaches that can be used to address concerns with living option supply, occupancy rate, and the resulting wait list length:
 - Queuing analysis, as described above, is a mathematical approach that would provide an understanding of the relationship between bed supply and the wait list (queue).³⁶
 - Discrete-event simulation (DES) is a computer modeling technique that is used to model a network of queues in detail. Given the complexity of the system of service areas and zones in the continuing care system, as well as the various levels of care, DES may be required to understand how the interactions of these individual facilities and areas affect the wait for care. DES would also provide confidence intervals for any estimates of system performance.³⁷
 - System dynamics (SD) is another computer modeling technique that models the 'stocks and flows' of patients through a system. It can provide a higher-level view of the changes in groups of patients over time and in separate facilities. This can be particularly useful when the complex flow relationships/dependencies as shown in Figure 2 exist.³⁸
2. The model used to predict how many patients each year will require entry into continuing care must be separated from the calculation of the number of living options that will be needed. The two predictions are closely related but because of variability in demand and the independent variability in capacity they have to be calculated separately. Even if the average number of new living options created each year (either as a result of new spaces being built or existing spaces becoming available) is equal to the average number of new patients requiring a living option a substantial queue is still possible because of variability.
3. The number of spaces needed to obtain a target average wait time cannot be predicted without applying queuing theory. Queues for continuing care living options will depend on factors other than the average number of new patients per year and the average length of stay. For example, if 365 new patients are expected to arrive per year and each patient stays an average of five days, it is not the case that the system will need exactly five spaces for these patients. Variability in the arrival pattern and in the length of stay will invalidate such a calculation. For example, imagine dividing the 365 patients into two groups. In the first group, one patient arrives each day and stays for a day; from the second group, a patient arrives every day and stays for nine days. The variability and the challenge to planning becomes apparent. In the simplest situation, that of a single independent facility, the required number of spaces to achieve a given target wait time, or wait list length, is a function of the following elements:
 - The current census of patients and their expected remaining lengths of stay
 - The average arrival rate of new patients
 - The variation in the times between arrivals
 - The average length of stay

- The variation in the length of stay
- 4. The continuing care system is not, of course, a single, independent facility; it is a large network of facilities and services of different types. Since demand and bed supply will not be held in aggregate at the provincial level but in many service areas across the province, the occupancy rates (and hence wait lists) in each service area for each type of facility will be more variable. The variation in a stream of arrivals is always greater for smaller populations. Hence, aggregate modeling of demand at the provincial level does not guarantee that an appropriate level of bed supply will result at the local zone or service area level. These and other complexities can be dealt with through queuing analysis and simulation modeling.
- 5. No forecast is certain. Thus there are generally accepted procedures from the science of forecasting for presenting a range of forecast values. Such a range is known as a confidence interval, and it indicates with, say, 95 per cent certainty the range of values within which a future value is expected to fall.
- 6. In modeling a system like continuing care it is important to list the assumptions that underlie the results, as different assumptions can lead to very different conclusions.
- 7. Prediction models should be validated as much as possible; this can be done by testing models using historical data (if available) and then determining how well the model predicted what actually happened.
- 8. Modeling is a means to an end; therefore, the end or goals should be clearly stated and models used to demonstrate how to achieve those goals. Key performance measures such as maximum wait time for a continuing care living option or percent ALC days can be used to ensure that the model is aimed at the right target.

Continuing care capacity forecasting

AHS has developed a planning model to forecast the number of continuing care spaces required to meet the needs of Albertans for the next 20 years. Projected total demand growth has been based on estimations of population growth, population aging, and changes in disease prevalence, and it has incorporated information about ideal living options for people currently waiting in acute care or waiting in the community. The approach AHS used in the 20-year needs assessment is mathematically more robust than the approach used historically within the previous health regions.³⁹

However, some limitations were identified with the methodology:

- The model predicts demand (number of patients needing access to continuing care each year) but does not separately predict the number of living options that will be needed based on setting performance goals and accounting for variability in demand and capacity. Performance goals (e.g., per cent occupancy, median or 80th percentile waiting time) are not explicitly stated.
- It is not evident that queuing theory has been considered in the analysis that generated forecasts for number of spaces. Without this there is no realistic way of relating forecasted demand, forecasted capacity, the variability in each over time, and the number of people in the queue and average queue length.
- The model currently applies both provincial parameters and Level III service area parameters to estimate Level III service needs.

- Confidence intervals are not provided for the estimates of demand for continuing care living options, thus the report fails to consider the inherent uncertainty in the forecast. Each estimate is presented as a point estimate, with no indication of how far apart this estimate and the actual value could be. Confidence intervals for the forecasts rely on a measure of forecast error. Forecast error can be estimated by comparing earlier forecasts against the actual realized values obtained after the forecast. There is no indication that the magnitude of past forecasting errors has been taken into account. Recognizing forecasting errors may remove some of the uncertainty surrounding a point estimate and thus would be valuable in this type of modeling.
- Such forecasting errors may shed considerable light on the uncertainty surrounding a point estimate and thus would be invaluable in this type of modeling.
- Information about the key assumptions made in calculating the projections is not provided in the document; for example:
 - Assumptions about the transition patterns between levels of care and the rates of transition from one level of care to another have to be made. Is it assumed that patterns and transition rates will remain the same as currently, or are expected changes in these patterns and rates incorporated in the forecasts?
 - Is the length of stay, on average and as a probability distribution, expected to remain the same as current? Since the report suggests that patient acuity will increase in all settings, assuming the average length of stay (which is a key contributor to wait times) will remain at current levels may underestimate the number of continuing care living options required over time.
- Four target mix scenarios (requirements for continuing care services) are presented and it is probable to some extent that any of these could occur. Predictions for continuing care living options are focused on only one of the scenarios, however. A better approach would evaluate the probability that any of the scenarios could occur and include a range of possible estimates.
- Five key parameters are considered in the current forecast model (current utilization per weighted population; disease trends; service volume; service mix; and wait times). It is suggested that other demand parameters for continuing care (e.g. socioeconomic status) be researched regularly to identify how they are projected to change over time and incorporated into the model as appropriate. Additionally multivariate regression could be used directly on past demand data to determine if there are other important factors that could help explain (predict) usage of continuing care living options and thus improve forecasts of demand for services.
- There is no evidence that consideration was given to use more advanced modeling techniques such as discrete event simulation or system dynamics.

In interviews, respondents indicated the forecasting model was significantly better than what had been used previously. It appears to be effective in forecasting two to three years ahead (the timeframe for which the model is most accurate) and is updated yearly. Based on the assessment document, funding decisions regarding where to construct the next available living options are being made collaboratively by Alberta Health, Alberta Infrastructure, AHS, and Alberta Municipal Affairs.

Policy development and review

Transparency of decision-making

"Policy translates vision into a consistent course of action".³ As described in the *AHS Governance Document Framework Clinical and Corporate*, policies "set out the organization's position on a specific subject, providing a common frame of reference and direction by establishing minimum requirements and expectations, that benefit those we serve".⁴⁰ The document identifies the required elements in policy development and implementation, including initiation, development, consultation (internal and external if required), endorsement and approval (to demonstrate the organization's commitment to uphold the requirements set out in the policy), implementation, evaluation, and review (periodic and ad hoc). It also notes that policy requirements may be expanded through other governance documents such as procedures, protocols, standards, codes of practice, or guidelines. In addition, each governance document (e.g., policy) must be "consistent with the Principle Statements" (i.e., reflect AHS vision, mission, and values).⁴⁰

AHS's mission is to "provide a patient-focused, quality health system that is accessible and sustainable for all Albertans".⁴¹ The organization has identified seven values that are intended to "lead our work, our actions, our decisions".⁴¹ The seven values include respect, accountability, transparency, engagement, safety, learning, and performance. Transparency is being clear about what and how decisions are made; these were identified by many interviewees as the reasons for having the FAALO policy. Although creating a policy and achieving provincial consensus on the content of the policy has been described as difficult, it was heard in interviews that the intent was to align with many of the stated values of AHS, especially transparency. However, some of the clauses, in particular 5.1 – 5.4, in the April version of the FAALO policy are perceived as being incongruent with the stated value of respect (valuing patients and families, demonstrating compassion, and treating others with respect, fairness and dignity).⁴¹ Most interviewees commented that this resulted in ongoing disagreement and ambivalence regarding wording in the policy.

While some interviewees believed this was a crisis policy that would be unnecessary once the supply of continuing care living options more closely matched people's needs, others believed that as long as there is a desire or commitment to allow patients to choose a preferred location, the decision-making process would still need to be explicit. In addition, as overall patient needs within continuing care become more specialized, access to particular services within one's community of origin cannot be assured. This will necessitate some ongoing co-ordination of access to those locations capable of delivering more specialized services, such as renal dialysis and programming for behavioural challenges in persons with dementia, for example.

Direction to staff

The FAALO policy is intended to provide consistent and explicit direction to transition services staff, case co-ordinators, case managers, home care workers, and others working directly with patients and families striving to make fully informed, consistent, and equitable decisions about access to scarce resources. Several interviewees emphasized the importance of ensuring this policy had administrative and political support to ensure those individuals making these difficult decisions were 'not abandoned'. While striving for consistency, some flexibility was seen to be necessary as well, with some interviewees identifying a need to maintain the ability of case managers to use their clinical judgment to address

unique individual circumstances. As one interviewee said, "individual problems may require individual solutions" and policies need some flexibility.

Some interviewees expressed concern that frontline staff have been placed in a difficult position with the decision to return to (or continue with) the use of legacy policies. This has resulted in inconsistent practices across the province, and with the changes in zone composition from legacy health regions, some zones may have more than one legacy policy to consider.

Legacy policies on wait list management

As identified previously, a number of legacy health regions had policies or practices to manage continuing care wait lists. These legacy policies are summarized in Table 1.

The table compares the legacy policies and the current AHS FAALO policy. There were different regional approaches to managing the continuing care wait list, with seven regions having a policy or draft policy, procedure, and/or directive. Two regions had an understood process but no formal policy. Five regions asked patients to identify choice of locations and five regions (not the same five) identified some sort of negative consequences or penalty if people refused the first available living option they were offered. Others identified a process to continue to find a viable placement but were clear that remaining in hospital was not an option. These legacy policies were used as the basis for the development of the FAALO policy.

Since the AHS policy was withdrawn, the legacy policies are currently in effect, resulting in inconsistent practices throughout the province.

Table 1: Policies from former health regions: Continuing care wait list management

	AHS	Chinook	Palliser	Calgary	David Thompson	East Central	Capital	Aspen	Peace Country	Northern Lights
First available bed	Yes – Continuing Care Wait list: Access to Living Option	Yes – policy and procedure First Available Bed for Placement of CC Clients Waiting for Urgent Placement from the Community or From an Acute Care Hospital	Draft – not implemented (understood process)	Yes – operational policy Offering FAALO & Transition and Admission to CC Facilities: “No Preference Admission”	Yes – policy Access to Residential Continuing Care Services	Yes – if critical acute bed shortage First Available Bed	Corporate administrative directive Planning for Alternate Levels of Care	Yes – operational policy First Available Bed	Yes Wait list Management	(understood process)
Year created Year revised	2013	1997		1997 2003	2006 (replaces previous)	2008	1999	2006 2008	1998 2008	
Placement from community	Yes	Yes		Yes	Yes	No	Not sure	No	Yes	
Specified distance	Removed May 2013	60 km		Not stated	80 km	Not stated	Not stated	100 km	60 km from current acute site; some exceptions	
Process for stating choice of sites	Yes	Identifies choice		Identifies preferred site	Can identify preferred site including outside region	Can identify choice	Not stated	Not stated	Two sites in region; can request outside region	
Description of wait list process	Yes	Has procedure		Describes process	Describes process	Has procedure	Has procedure	Has procedure	Procedure: has CC Regional Placement Office	
Information provided	Transition process and charges	Yes		Not stated	Not stated	Not stated	Yes	Not stated	Not stated	
Response to refusal of FAALO	Taken off wait list	Billing for acute care accommodation; negotiation continues; bed kept for 5 days		If accepts, will not lose place on list; charged daily rate for non-entitled	Discharged home with home care; charged per diem acute care rate	Notifies patient/family in writing of non-discretionary requirement to relocate	Continue negotiation	May charge average CC daily rate (\$192)	If refuses first choice: removed from wait list; discharged home or pay acute care non-entitled rate. If not first choice, pays for excess costs above max home care.	

	AHS	Chinook	Palliser	Calgary	David Thompson	East Central	Capital	Aspen	Peace Country	Northern Lights
Appeal mechanism	Not specified	Negotiation continues – referred to administration		Not stated <i>Hospitals Act</i> - trespasser	Appeal Process Policy	Not specified	Dispute referred to senior level of management	Not specified	Yes	
Charges	\$100/day for standard hospital room accommodation	If refuses, billed for acute care accommodation		If refuses, charged daily rate for non-entitled individuals	Effective date of ALC designation	Not stated	If refuses charged difference between per diem in acute and CC site	If refuses, charged per diem \$192		

Evolution of the AHS FAALO policy

Given the historical and current situation in Alberta of inadequate continuing care spaces to meet demand, a wait list is inevitable. At the end of the fourth quarter in 2012-13, there were 453 people waiting in hospital and 701 people waiting in community settings (a combined total of 1,154) for access to a continuing care living option.^{42(p 62-63)} How the wait list is intended to be managed is described in the document, Co-ordinated Access to Publicly Funded CC Health Services: Directional and Operational Policy, [dated] April 15, 2010. This document was developed collaboratively between the Government of Alberta, Alberta Health, and AHS.³

The directional policy for managing the wait list specifies that "clients for whom the optimal service option or setting is not immediately available are assigned to a wait list and prioritized based on the urgency of their assessed unmet need".^{3(p 9)} Interviewees stated that the directional policy was apparently "never released publicly by Alberta Health" but it has been used as the foundation for AHS co-ordinated access policies.

Shortly after AHS was created in 2008, work began on creating a provincial approach for access to continuing care services to create consistent practice and equitable access for all Albertans. Interviewees highlighted how much has been accomplished since that time, including consensus that a provincial approach is preferable, though some flexibility may be needed to address rural and urban differences.

The development of the current policy has been an arduous, six-year process. A perception exists that an extraordinary amount of time and attention has been devoted to the ongoing attempts to develop a policy acceptable to AHS executive and subsequently Alberta Health. In interviews, there were different beliefs as to whether the policy had been approved by the AHS Executive Committee in November 2012. Documentation review found that draft policies had been updated based on feedback provided by the AHS Executive Committee and Alberta Health.

An agreement was made between AHS and Alberta Health to pilot the policy in Edmonton and Calgary. The pilot was conducted from January to March 2013. An undated evaluation report of that pilot was completed with three key recommendations^{43(p 2)}:

1. Transition the pilot implementation to operational practice in Edmonton and Calgary zones immediately.
2. Implement the companion policy, *Continuing Care Waitlist: Prioritization*, to provide greater clarity in the 'expedited return' to the site or location of choice from the temporary placement to the first available living option.
3. Implement both policies throughout the province as AHS Level 1 policies.

In May 2013, the then AHS CEO and the Minister of Health requested an internal review of the necessity of the FAALO policy in Alberta and of the need to a 100 kilometre distance limit from a person's preferred location. AHS analyzed data from 100 patients in each zone to determine how far people were actually moving when accessing continuing care. At the same time, other changes were made to the policy, creating the May 8, 2013 version titled *Continuing Care Waitlist: Access to Living Option*.⁴⁴

The findings from the pilot and the above government requested review are summarized in Table 2. At the time a living option was given to people, 67 per cent (293 people) in Edmonton and 42 per cent (173 people) in Calgary were offered their preferred option. In Edmonton, of the 33 per cent (142 people)

whose first choice was unavailable, 17 patients initially refused the FAALO with the following outcomes: nine accepted after further discussion, five went home, two were matched to the next FAALO site, and one went to respite care. No patients were taken off the wait list and no patients were charged the additional accommodation rate. Most people (71 per cent) were offered a living option within 40 kilometres of their first choice.

"Case managers report that initially a significant number of patients refuse a FAALO, but after a careful exploration of options, acceptable alternatives are identified."^{43(p 6)} Reasons for refusal were cultural, objection to the environment offered, and a concern about the length of the wait list, not the 100 kilometre distance.

The pilot conducted in Edmonton and Calgary between January 15 and March 15, 2013 was considered by authors of the report to be "too short [a time] to capture the number of days from admission [to a FAALO] to date of admission to preferred location".^{43(p 5)} Given the short duration of the pilot, the authors noted it was not possible to identify those who were admitted to the first available space and then subsequently decided to remain there.

It was heard through interviews that some of the data were difficult to collect and much of the information was collected manually. Thus the HQCA was unable to validate the data.

Table 2: Summary of findings of pilot and government requested review conducted by AHS in 2013

Data Obtained	Pilot Edmonton & Calgary January 15 – March 15, 2013	Government Requested Review Used data October 1, 2012 – March 31, 2013 (Q3 & Q4); review ended June 30, 2013 All AHS zones
Total number of people offered living option	Edmonton: 435 Calgary: 413	Used 100 patients from each zone; n=494
Percentage and number of people who were initially offered a preferred choice	Edmonton: 67% (293) Calgary: 42% (173)	57% (284) were offered first choice 10% (51) offered second or third choice Zones: South (79%); North (77%); Central (59%); Edmonton (43%); Calgary (28%)
Time to be placed in one of preferred options	Pilot period too short to determine	As of June 30, 2013 - 65% (33) still waiting
Percentage and number of people who were offered a FAALO	Edmonton: 33% (142) Calgary: 58% (240)	32% (159)
Travel distance from first choice preference	Not monitored	71% (112 people) - 40 km or less Distances farthest in Central Zone and closest in Edmonton Zone 3 people >100 km (1 each from Central, North and South zones; not known if this was patient choice)
Those who offered FAALO and then offered move to preferred option	Interval of pilot too short	32% (159); by end of study 50% (80) offered move to preferred option: 68% (54) accepted transfer; waited average of 62 days 32% (26) declined transfer; waited average of 86 days 50% (79) not yet offered transfer to preferred location
Still waiting to move		North: 13% (3); Edmonton: 81.5% (31); Central: 7% (3); Calgary: 71% (40); South: 9.5% (2)

Some interviewees felt more effort could have been made to follow up with those who had accepted the FAALO space to ensure they ultimately did get to their preferred option. Some questioned if the average length of time it takes to get admitted to each site (especially those in high demand) could be provided to patients and their families, and ideally, made public.

A number of interviewees emphasized that the FAALO policy (which describes how decision-making occurs in arranging access to a living option) "should not (and cannot) be seen as a stand-alone policy" but rather considered with the *Continuing Care Waitlist: Prioritization* policy (which determines priorities for moving a patient between continuing care facilities, and ensures someone who accepts a first available option is given priority placement to a preferred location when a space opens).⁴ Two companion policies were also created to focus on the charges incurred by ALC patients, *Alternate Level of Care Accommodation Charges – Patients Waiting for Continuing Care*⁴⁵ which identifies the accommodation charges all patients waiting for transfer from acute care to a continuing care living option will incur and *Continuing Care Charges Reduction*⁴⁶ to remove any financial barrier that could prevent access to a continuing care living option.

In the May 8, 2013 version of the FAALO policy, AHS changed the policy name from *Continuing Care Waitlist: First Available Appropriate Living Option Policy* to *Continuing Care Wait list: Access to Living Option*. Other wording changes include:⁴⁴

- Any reference to 'first available appropriate living option' has been replaced with 'temporary living option'. Interviewees noted the change in language was to emphasize the temporary nature of this first placement and reflect a commitment to offering a space in a preferred location when available.
- The reference to a specific kilometre distance has been replaced with a clause indicating "the patient/alternate decision maker will be provided with information on living options immediately available in order to choose a temporary living option". Adding the clause "as near as possible" is also being considered.

In interviews, two perspectives were presented as to why the 100 kilometre distance was removed. Omitting any reference to a specific distance may well have removed a 'lightning rod' that seemed to cause immediate criticism of the entire policy. On the other hand, it has also removed the transparency concerning distances that could be considered when moving patients to a temporary living option.

As summarized by one interviewee, "we have been feverishly working on how to standardize a very challenging, politically charged policy for all the right reasons...but the fact remains, we don't have enough living spaces in this province."

Factors considered when choosing a continuing care living option

The patient and family interviews (Appendix V) identified a number of factors that were relevant to their decision-making in choosing a preferred living option. Location was mentioned often and referred to remaining close to friends and family, whether the site was in a safe neighborhood, in an area that fit for the individual (e.g., small site on an acreage for someone who loved the outdoors), or how easy it was to travel to the site for the spouse or family. Many interviewees expressed their concern about separating someone from their family and friends.

Other key considerations included language and cultural sensitivities, private versus semi-private or three person rooms, and available services (e.g., physiotherapy). Interviewees identified that 'ratings'

from the internet or others who were familiar with the site was also important. One family member commented that having other levels of care on the same site was seen as a positive.

If a site visit was able to be arranged prior to the move several patients and family members described how influential the 'feel' of the site was. This was described as how the staff interacted with the patients, cleanliness, security, and whether the environment was 'homey'. Homey referred to the ability to open windows, enough space for personal effects, places to relax outside of their room, and cats or dogs in the facility.

Hopper identified that understanding how wait lists are managed (i.e., factors influencing placement on a wait list, not just date of being put on the list) is important in the identification of preferred sites. For example, if the wait time to access a particular site was extremely long (e.g., years) it was not considered to be a realistic option.⁴⁷

Many interviewees stated that being separated from family and friends is a significant worry for seniors moving into continuing care. An advisory group including patient and family representation, consulted as part of the AHS internal review, readily understood the need for a FAALO policy and thought it was important to specify a distance limit to convey the maximum distance one would be moved from home or a preferred location, thus protecting an individual from being moved farther. This was consistent with the stated intent by a number of interviewees who had worked on the policy. Moreover, it was felt that people must have the choice to move farther than 100 kilometres away if it brings them closer to family members in another part of the province. According to AHS, the distance of 100 kilometres would accommodate both rural and urban moves, and would enable a consistent provincial approach.

Interviewees pointed out that it is important to consider that on an individual basis, any distance can create a challenge for people with no means of transportation, whether it is 10 or 100 kilometres from home. In some cases, even travel across a large city can be onerous. This may be a particular challenge in rural and remote areas that lack an appropriate and available facility within 100 kilometres and where transportation services may be limited.

If a patient was happy in the facility, the care was good, and the staff knew and treated the person well, then moving to a facility closer to the family was no longer necessarily the most important concern.

Corporate policy development

The Corporate Policy Department and the Clinical Policy Department within AHS provide direction to the organization to standardize the processes for developing and implementing corporate and clinical policy as outlined in the *AHS Governance Document Framework Clinical and Corporate*.⁴⁰ As mentioned previously, the work on a provincial approach to managing the continuing care wait list within AHS started before the end of 2009 with stakeholder consultations on draft policies.

The FAALO policy has had different sponsors and champions throughout its development. Although each draft is date-stamped, it is not easy to follow the multiple drafts, nor was a summary document available that could have captured all of the changes from one version to the next with a chronological history of why clauses were included or removed (e.g., the appeal mechanism).

The level of involvement of the two policy departments is said to have varied over time, which may account for some of the challenges in document management, identification of which key groups needed to be consulted, and ensuring all the necessary supporting documents were in order when the policy was sent to the Executive Committee for approval. A few interviewees speculated whether the

inconsistent involvement of these departments may have contributed to the length of time it has taken to get the policy approved. It was suggested that perhaps if all the steps had been followed and supporting documents developed, the policy might have been better understood and approved earlier. Interviewees also stated that, although the *AHS Governance Document Framework Clinical and Corporate* was the preferred methodology to develop policy, as of summer 2013, it became "a reference document only".⁴⁰

Policy evaluation

The *AHS Governance Document Framework Clinical and Corporate* includes a section on accountabilities and responsibilities, and specifies that the "policy representative provides support to sponsors for the development of an evaluation strategy to be used to create an operational evaluation plan".⁴⁰ Evaluation is identified as an explicit action, in order to assess "success in achieving the desired outcomes identified during initiation and development and compliance with the requirements".⁴⁰ It is not clear whether the evaluation methodology needs to be determined prior to implementation. The framework identifies evaluation as a quality improvement step with a specified timeframe (generally three to six months after implementation) to determine compliance with the requirements, and the appropriateness, efficiency, and effectiveness of the document to determine if the issue has been adequately addressed and whether desired outcomes have been achieved.

An evaluation plan was apparently to be developed once the FAALO policy was approved and ready for province-wide implementation. The documentation review found a reference to an "implementation plan, which should be inclusive of the education and evaluation plans as well as the communication plan", however the HQCA was unable to confirm if an evaluation plan had been developed.

Stakeholder consultation

In the *AHS Governance Document Framework Clinical and Corporate*, stakeholder consultation is considered "crucial" to ensuring that issues are identified early to avoid problems with implementation.^{40 (p19)} Stakeholder feedback on the FAALO policy from within AHS and some external organizations, such as Covenant Health sites, was compiled into an extensive document in November 2009.⁴⁰ Stakeholder concerns included the separation of spouses and distance between them and related transportation difficulties; increased demands on home care; and the need for adequate public consultation. Stakeholders expressed that managing family concerns during the period of waiting for a preferred option was important, as was guiding patients and their families on what to expect during a transition in care. A family-centred approach was recommended to resolving issues about placement, rather than a confrontational approach that would see people removed from a wait list for refusing the first option given, which was specifically not supported by stakeholders.

Interviews conducted by the HQCA could not confirm if all the concerns were addressed and whether changes were made to subsequent drafts of the FAALO policy based on the input. There is documentation discussing how some, but not all, of these identified issues would be addressed. Interviewees wondered if the process of policy development could have been more rigorous to ensure identified issues were resolved thoroughly and the solutions communicated to those raising the issues. It is acknowledged that such a process would require significant time and attention, but given the sensitive nature of the proposed policy, addressing those concerns before seeking policy approval may have prevented some of the negative reaction when the policy became public. In fact, many of the issues reported in the media were actually raised by stakeholders in 2009. It was noted in interviews that the

policy had received so much negative attention that it will be difficult to effectively communicate why the policy is necessary, what it is intended to achieve, and how it will be implemented.

It was also suggested by interviewees that it may have been useful to ensure there was adequate public consultation during policy development, as the public is a key stakeholder. According to the AHS *Governance Document Framework Clinical and Corporate*, there is an opportunity to consider the need for community engagement where "the sensitivity and/or severity with which the public perceives these topics may warrant action".⁴⁰ The documentation review did not identify or reference a community engagement plan, however it was noted that feedback was sought from the AHS Patient and Family Advisory Group.

How interviewees characterized ethical concerns

The April 22, 2013 version of the FAALO policy identifies that the policy is based on "ethical principles such as fairness and equity - individuals who accept a FAALO are entitled to transfer in priority order..."⁴¹ In spite of this principle, as mentioned in several interviews, people felt coerced to accept the first available option or face perceived negative consequences.

According to the AHS *Governance Document Framework Clinical and Corporate*,⁴⁰ the subject matter of the policy will dictate if Clinical Ethics and the Ethics and Compliance Office should be consulted. In the development of the FAALO policy, informal feedback was provided by the ethics service in February 2010, which included comments on divergent views about the 100 kilometre limit and how best to identify appropriate distances for rural and urban settings. In addition the ethics service suggested the importance of keeping the patient informed and involved in the process as the current policy was "quite system focused". HQCA enquiries found no evidence that a formal ethics review of the policy was conducted.

In interviews with key informants, opposing perspectives on ethical issues were raised about the policy, including:

- Keeping people in the hospital unnecessarily was seen as unethical because it is known that a prolonged hospital stay can be harmful to one's health and "is almost guaranteeing facility living". Because of the principle of 'do no harm', this was seen as the top patient safety concern, overriding patient choice of location. It was felt that although patients' choice may be constrained, patients would at least be in a setting appropriate for their needs. A comparison was made to other situations in which individual choice is removed for the safety of a larger population, such as laws about drinking and driving. It was purported that "as a society we condone removing choice if that action removes harm to others".
- Keeping patients waiting in the emergency department for an inpatient bed occupied by someone waiting for an alternate level of care was seen as unethical. A desire to have this policy consider all patients and the larger system implications was emphasized by more than one interviewee.
- Restricting choice was seen as unethical if patients feel pressured to accept a temporary move to a site not of their choosing. Such a scenario was seen as coercive, and adding an additional move to a patient's experience. It was acknowledged that any move may be stressful to an elderly patient recovering from an acute health episode.

- Treating all people the same was viewed as unethical and it was felt some flexibility is warranted to ensure individual needs, including culture and language, were considered in the placement decision.
- One interviewee identified that the values conundrum for health leadership should be to address the capacity gap because by not doing so, a no-win situation is inevitable.

In a presentation by an AHS Transition Services Manager and an Ethicist entitled, *Whose Bed Is It Anyway? An Ethical Analysis of the First Available Bed Policy*, it was concluded that: (1) the policy could be argued to be ethically justified, (2) many of its challenges are system issues, (3) ethical evaluation includes both content and process, and (4) attention to process might help to offer improvements.⁴⁹

The transition to continuing care

As discussed, inadequate continuing care capacity creates the need for a wait list. That wait list requires a policy to specify how continuing care living options will be filled. Meadus and Wall state that "these patients are not mere numbers in a bed flow process; they are people".^{50(p 10)} These are individuals coping with a stressful life event: the loss of independent living. How they and their families decide where they would like to live, perhaps for their remaining years, is difficult. How the transition from home or hospital to a continuing care living option is supported and managed becomes a key outcome of how the FAALO policy is implemented.

One guiding principle that has been identified as fundamental to the understanding of the transition from hospital to continuing care is replacing the concept of 'discharge' with that of 'transition'. Discharge, by implying that 'the patient is no longer our responsibility' after he or she leaves a facility, is an "outmoded concept"⁵¹ that contributes to a lack of continuity of care, a key quality and safety issue. Transition, by contrast, extends providers' responsibility for a patient between one level or setting of care and the next. This language is more in line with the idea of an integrated healthcare system, rather than separate entities or sectors (sometimes referred to as silos) of service such as acute care and continuing care. Gruneir et al highlight that transitions between healthcare settings are increasingly recognized as a time when older adults, especially those with complex needs, are particularly vulnerable to complication or error.⁵² Transitions, for example initial admission into LTC, are implicated in contributing to a greater risk of adverse outcomes, as a transition represents a change in both healthcare setting and life stage. The new environment, new routines, and lack of familiarity with staff increase the potential for adverse events.

"It is an acknowledged fact that the transition to a care home is likely to be a stressful event".⁵³ The North American Nursing Diagnosis (NAND) acknowledges relocation stress as a recognized disease.⁵⁴ No research or documentation was found on whether this second move is easier when patients move by choice.

The literature supports the experiences of family members who describe nursing home placement as one of the most difficult life events they have ever faced, causing feelings of avoidance, guilt, sadness, and regret along with feelings of relief and peace of mind.^{55(p 4)} While conceptual models describing the conditions that support or impede positive transitions are only beginning to emerge, five conditions are understood to be relevant to various stages of the transition. These include being in control (able to maintain ownership of decisions), being in the know (having access to information), feeling supported (others are aware of the consequences of the move, willing to listen, and available for the family),

working together (being able to work with healthcare staff to ensure the best care for the older person), and feeling no pressure (encouraged to take time to make decisions).⁵⁶

In interviews, several participants noted there are some initiatives in Alberta to make acute care more 'senior friendly' with the introduction of practices such as comfort rounds, for example, that ensure elderly patients are attended to at least every two hours. These participants noted that while patients are in hospital, even if they are approved and waiting to move to a continuing care living option, staff and physicians do have a duty to care for them to the best of their ability. Acute care is, therefore, also part of the solution in ensuring an effective transition.

Interviews confirmed that researching and identifying preferred sites is complicated by the need to make decisions within tight timelines, identified as being an extremely stressful time for patients and families. Several interviewees emphasized that the way and how the discussion about the transfer happened are critical to a family's ability to deal with the process. Further stress is added when people are asked to accept a temporary placement (the first available option) to wait for access to a preferred site, meaning they may move at least once more.

Patients and families concerns often focused on the short time frame for making a decision, the lack of information to help with decision-making, and their limited understanding of the transition process. The language that patients and their families used to describe their experiences, even when the outcome was acceptable, indicated that they felt left out of the decision-making. The lack of control and uncertainty is what people found most stressful and upsetting about the experience. Most people said their interactions with staff from transition/placement services were good, but perceived that staff were "struggling to work in an imperfect system". Several patients and their families felt they were abandoned after moving into a FAALO living option.

Concerning moves into continuing care from community, timing had a great bearing on how well the transition went. Sometimes the move happened sooner than expected, and the individual or family did not feel emotionally ready to cope with the change. At other times, the wait for a bed was too long, jeopardizing the well-being of the main caregiver at home. Patients and their families expressed that they appreciate being able to work closely with someone who can help them make informed choices that meet their needs. Interviewees described positive experiences of this kind, many taking place in smaller towns or cities.

Transitions in Continuing Care: Literature Review and Best Practices is a comprehensive review prepared by Co-ordinated Access/Transitional Services, Seniors Health Strategy Portfolio, AHS, describing why transitions are critical periods in an individual's journey of care, as well as which interventions make transitions more or less effective.⁵⁷ The report notes "if one is to help an individual through a transition, it is important to understand their point of view, their past experiences with change, previous coping skills, and what losses or potential losses that person perceives".⁵⁷ The document includes a discussion on transitions (personal, health status, and healthcare), the role of the patient and family, ways to identify people requiring transitional care, models of transitional care (e.g., hospital-based models, comprehensive geriatric assessment, care transitions intervention model), barriers to effective transitional care, and best and promising practices.⁵⁷

Some patients, particularly those who have had an acute episode requiring hospital admission, may require a period of recovery and rehabilitation to reach or return to their optimal functional level. AHS

has a number of options throughout the province to facilitate this recovery including subacute units, transition units and specialized geriatric units.

Accessing information

When a patient is ready to be discharged from hospital, but requires ongoing support and services, the individual and family are expected to identify a preferred living option. It was expressed by interviewees that it can be difficult to get information about the available options. The Alberta Health website and the case coordinators who provide information about options were felt to be insufficient sources of information. It was stated that it would be helpful if an information package of some sort were readily available to families to help with decision-making. This was one of the key findings in a 2008 study conducted in two large regions in Alberta that concluded: "Although some information is available in both regions on the operation of wait lists, more is needed...more detailed written information about how the wait lists operate...emphasizing that the wait list is not a sequential queue...but rather multiple factors affect wait times including the nature of care needs (urgency, complexity), availability of beds in specific care facilities, and the presence of client behaviors or other characteristics that make admission relatively difficult."⁴⁷ The authors suggested educational materials also be available to professionals working in healthcare centres (acute and rehabilitation settings), primary care networks, and other agencies associated with seniors services (e.g., Alzheimer Society, day support programs) so that sharing of information could start sooner. It was also noted that publications should include details about obtaining home care services, as family members reported they began to think about the need for help early in the process but did not know the range of options available.

Families are encouraged to contact individual sites, ask questions about the services provided, and if at all possible tour potential living options. Unfortunately, there is not always enough time for such visits to be arranged. More than one interviewee suggested that information about services and wait times for individual sites should be more readily available to the public and gave the example of the HQCA having, but not posting, site-specific information. In one legacy policy in Alberta, people were given five days to gather information while a bed was kept available for them. Across the province, there are variable times given to patients in acute care to decide on a continuing care option.

SUMMARY OF QUALITY ISSUES

The HQCA's Alberta Quality Matrix for Health³⁵ was used to summarize the key quality issues related to the management of continuing care capacity.

Acceptability

FAALO does not respect a patient's preferred choice(s) and is not responsive to a patient's needs, preferences and expectations:

- Potential negative consequences if FAALO refused
- Inadequate information provided to patients and families that allows them to make an informed decision
- Time pressured to make significant life event decision
- Patients/families experience lack of control and uncertainty about the transition to a continuing care living option
- Patients/families feel abandoned after moving into a FAALO bed

Accessibility

- Continuing care capacity has not adequately met the demand for these services leading to excessive numbers waiting and prolonged wait times for a preferred continuing care living option which leads to,
 - excessive numbers waiting and prolonged wait times for ED patients requiring an inpatient bed which leads to,
 - excessive numbers waiting and prolonged wait times for patients in the ED.
- Patient may not be a reasonable distance from family and friends when placed in a continuing care living option.
- Lack of access from community may lead to avoidable ED visits and acute care admissions.

Appropriateness

- Continuing care capacity planning and/or capital planning execution has resulted in an inappropriate number and mix of supportive living and long-term care living options; resulting in some patients not being in a location that is relevant to their needs. (e.g., ALC patients in acute care, patients waiting in the ED for admission to acute care; patients assessed for supportive living but placed in long-term care).

Effectiveness

- Environments that are not appropriate for patient's assessed needs put them at risk for functional decline and suboptimal outcomes.

Efficiency

- Using resource-intensive environments that are beyond a patient's assessed needs is an inefficient use of limited health system capacity.
- The FAALO policy can lead to use of limited health system resources to transition patients multiple times.

Safety

- Delayed transitions from acute care to a continuing care living option increase the likelihood of adverse events (e.g., delirium, pressure ulcers, falls, and infections).
- Transitioning patients to continuing care (during a critical life event) can predispose some to psychological trauma - multiple transfers would be expected to compound this risk.

ISSUES, ANALYSIS, RECOMMENDATIONS, AND REQUIRED ACTIONS

The review identified two key issues, with associated recommendations and required actions that offer opportunities to improve the quality of care and transitions for patients accessing a continuing care living option.

Issue

Making the transition to a continuing care living option is a significant life event. The healthcare system is unable to consistently respond with a transparent process that patients and their families find acceptable or appropriate.

Analysis

In a resource-constrained environment like continuing care, most stakeholders understand the requirement for a FAALO policy; however, many patients and their family experience the transition as highly stressful due in large part to how the process is managed. The limited information and time provided for making a critically important life decision makes it difficult for patients and their family to accept the process.

Once it has been determined that a person needs to transition to a continuing care living option, patients and families are encouraged to contact individual sites, explore the services provided, and if at all possible tour potential living options. An underlying assumption is that patients facing this transition should have some degree of choice in determining a living option. However, real choice is limited by the need to make decisions about their preferred options within tight timelines and a lack of information. Vital information, such as services available and wait times for individual sites, is not readily available.

Each patient and his or her caregivers should be asked what factors are most important for them to make the decision about their preferred options. The range of factors might include, for example, configuration of the personal space, location, environment (e.g., the 'feel' of the site), observations about how the staff interact with patients, and cultural and linguistic familiarity.

Alberta Health and AHS have stated that "coordinated access is a...province-wide, person-centred, integrated service access and delivery approach that provides Albertans with reasonable, timely and appropriate access to publicly-funded continuing care health services based on availability and determination of unmet need". Despite years of attempts, and multiple policy drafts, a provincial FAALO policy has not been achieved. Currently, without a provincial policy, the way in which patients are transitioned into continuing care living options varies widely and may create inequities.

Several clauses in the April 2013 FAALO policy have a punitive tone. These clauses spell out the consequences of refusing the first available, appropriate living option. There was strong agreement about the numerous ethical concerns with this punitive approach, because it is incongruent with the stated values of AHS. Yet, there was a belief that there had to be 'teeth' in the policy to be able to enforce a move to the first available living option when required, in order to minimize the inherent risks to patients of remaining in hospital when that level of care is no longer needed and to free up acute care capacity.

The FAALO and *Continuing Care Waitlist: Prioritization* policies are separate but interdependent AHS documents. The latter policy spells out how prioritization is determined among different patient populations (e.g., those in the community identified as urgent, and people in continuing care awaiting

transfer) as well as how organizational factors could impact the wait list (e.g., AHS overcapacity protocols).

Recommendation 1

Alberta Health Services develop and implement a:

- provincial *policy* for transitioning people to continuing care that:
 - assures principle-based decision making
 - incorporates elements that are congruent with AHS's stated values, and excludes elements that appear threatening or punitive
 - recognizes that in circumstances where due process has been followed and an acceptable solution cannot be reached, AHS has the authority to move the patient to a safe and appropriate living option (per Alberta Hospitals Act),
 - includes the right of appeal
- consistent and transparent provincial procedure for transitioning people to continuing care that:
 - provides strong decision support to assist patients and caregivers to specify their preferences
 - specifies when and how patients and caregivers will be presented with all appropriate living options that best match their preferences and assessed need
 - specifies reasonable timeframes for patients and caregivers to make decisions about the presented options
 - describes a resolution mechanism when the presented options are not acceptable
 - ensures those patients who are placed in a non-preferred living option continue to be supported, making it possible for them to transition to their preferred option at a later date

Required actions

- Include patients and caregivers and operators of continuing care services as key stakeholders in the development of the procedure and policy.
- Develop a decision support tool that incorporates the factors considered by patients and caregivers when naming their preferred continuing care living options (e.g., location, distance, cultural, language, and environment).
- Integrate the new procedure and policy with the AHS Continuing Care Waitlist: Prioritization policy.
- Undertake formal deliberative ethics input to the policy and procedure development that:
 - includes patients, families, caregivers, and other stakeholders.
 - specifies the ethical principles that underpin the policy and procedure elements.
 - describes how these ethical principles are balanced and apply to the decisions that patients and caregivers, as well as providers, encounter throughout the entire transition process.

- Develop an evaluation plan to determine and monitor the impact of the policy and procedure on patient experience and the quality and safety of care.

Recommendation 2

Alberta Health Services develop information that meets patients' and caregivers' needs and supports their ability to make informed decisions about available continuing care living options.

Required actions

- Collaborate with patients, caregivers, and continuing care providers in the development of the information, its dissemination and ongoing maintenance.
 - information provided could include: support services provided, wait time, age and size of facility, room configuration (e.g., single or shared, windows), cultural/language focus, location, additional costs, quality ratings/measures, aging-in-place options, pet policy.
 - information should be readily available in various formats (e.g., hard copy, on-line).

Issue

Historically and currently, to varying degrees in each AHS zone, continuing care capacity has not adequately met the need (demand) for these services. Measurement of variability in demand and in capacity is critical to the understanding and management of medium to long-term continuing care resources. Current reporting and modeling may not be sufficiently robust to fully support continuing care capacity management and forecasting functions.

Analysis

For several years AHS has been engaged in proactive planning of both the mix and the number of continuing care spaces. Adopting the successful strategy that the former Chinook Health Region used more than a decade ago, AHS has added supportive living spaces throughout the province. The net effect appears to be improved appropriateness of the living options offered to patients who need them. However, only in the Edmonton and North zones has the number of patients waiting for a continuing care living option decreased over the last three years (i.e., the match between demand and capacity is improving). The number has remained constant in the South Zone and increased over the last year in the Calgary and Central zones.

Alternate level of care (ALC) days as a per cent of total hospital days averages approximately 10 per cent across the province. This is an inefficient use of an expensive and constrained resource – acute care beds. In addition, other parts of the system are impacted such as, longer emergency department wait times and high acute care occupancy. Most importantly, this impacts patients. The cohort of ALC patients is not being cared for in the optimal setting to meet their needs. Furthermore, the care and experience of patients in many other parts of the healthcare system can be negatively impacted.

Managing the continuing care system capacity requires an understanding of the factors that determine the number of patients who are on a wait list and the average time on that list. These factors include:

- number of people requiring a continuing care living option (demand).
- available continuing care living options (capacity), which is dictated by the total number of living options available and residents' length of stay (LOS).

- variability in demand and available capacity over time.

Understanding the relationships between these factors, as well as their effect on queue length and time, are best explained by queuing theory.

Continuing care capacity should be managed by AHS using data on past and current state of demand and capacity as described above. Variability is best understood by graphically displaying demand and capacity data, and the degree to which they match up, over time. A common format for displaying data of this nature is statistical process control charts. Information displayed like this can also be easily compared with forecasted demand and capacity. AHS has recently started generating automated reports that address some of the data requirements for managing continuing care.

In addition to monitoring the current state, examination of forecasted demand and capacity over the short term (one to six months), intermediate term (six months to three years), and long term (three to five years) are also required. These forecasts should be used with modeling to determine the anticipated length of the wait list and wait time duration. There was no evidence that standardized reports, graphically displaying demand and capacity data over time for each of the continuing care living options (LTC, SL4, SL4-D, SL3), were routinely being used within all AHS zones to support the management of continuing care.

In the past three years AHS has taken a more disciplined and proactive approach towards forecasting continuing care resources province-wide by developing and using a Continuing Care Capacity Needs Assessment Model. The HQCA commends AHS for the considerable work that has been done to date and recognizes the associated challenges, especially when the data required to support forecasting are incomplete.

Prediction models have been created by AHS that look forward to 2032. These provincial models have used data on available continuing care resources with adjustments for the current shortfall in numbers of spaces and the ratio of different types of spaces (lower percentage of LTC spaces). The models have also incorporated demand forecasts based on projections of population growth, changes in aging demographics, and predicted changes in underlying disease complexity.

Although this type of modeling represents a considerable improvement in planning compared with previous efforts, it was recognized that the modeling may not be as robust as it could be for the substantial investment in infrastructure and human resources that is thought to be needed. The limitations with the methodology are highlighted below:

- The model predicts demand (number of patients who will require access into continuing care each year) but does not separately predict the number of spaces that will be needed accounting for variability in demand and capacity. Performance goals (e.g., per cent occupancy, median or 80th percentile waiting time) are not explicitly stated.
- The model currently applies both provincial parameters and Level III service area parameters to estimate Level III service needs.
- Confidence intervals are not provided for the estimates of demand for continuing care living options, thus the inherent uncertainty in the forecast is not considered. Confidence intervals for forecasts rely on a measure of forecast error. Forecast error can be estimated by comparing earlier forecasts against the actual realized values obtained after the forecast. There is no indication that the magnitude of past forecasting errors has been taken into account.

Recognizing forecasting errors may remove some of the uncertainty surrounding a point estimate and thus would be valuable in this type of modeling.

- Key assumptions, such as the transition patterns between levels of care and the rates of transition from one level of care to another, made in calculating the projections are not described in the Continuing Care Capacity Needs Assessment Model 2013-2032. Is the length of stay, on average and as a probability distribution, expected to remain the same as current?
- Five key parameters are considered in the current forecast model (current utilization per weighted population; disease trends; service volume; service mix; and wait times). It is suggested that other demand parameters for continuing care (e.g. socioeconomic status) be researched regularly to identify how they are projected to change over time and incorporated into the model as appropriate. Additionally multivariate regression could be used directly on past demand data to determine if there are other important factors that could help explain (predict) usage of continuing care living options and thus improve forecasts of demand for services.
- There is no evidence that consideration was given to use more advanced modeling techniques such as discrete event simulation or system dynamics.

Recommendation 3

Alberta Health Services create and use specific demand and capacity performance measures that will support decision-makers to manage the wait lists for continuing care.

Required actions

- Where data do not currently exist on continuing care capacity (e.g., per cent occupancy), develop data sources and methods for validation, then use AHS Data Integration, Management and Reporting's automated data reporting to make this readily available to accountable decision-makers.
- Create automated graphical data reports to optimally support AHS decision-makers' ongoing management of current resources. Such reports should display: 1) current and past state of the queues for continuing care services and the impact this is having on other parts of the healthcare system; 2) current and past demand and capacity data (and the degree to which they match); and 3) the extent to which current state compares with forecasted demand and capacity. For example, for each of the four types of continuing care living options for each AHS zone or service delivery area and, where relevant, for populations with specific conditions (e.g., patients requiring dialysis, ventilators, or programming for dementia-related behavioural challenges) develop graphs that show changes over time for:
 - queue length and average queue time for continuing care patients in acute care beds and in community
 - per cent ALC bed days in acute care
 - total demand over time
 - total capacity over time

- Develop a process for each zone to follow that uses data on demand and capacity to understand intermediate-range forecasts for continuing care living options and to have contingency options available to adjust for unforeseen changes in demand and/or capacity.
- Develop education and training for decision-makers on how to use demand and capacity data to maximize the use of standardized reports to influence decision-making.

Recommendation 4

Alberta Health Services engage independent modeling experts to review the current approaches that are being used to predict intermediate to long term demand and capacity in continuing care throughout the province.

Required actions

- Engage operations management experts to advise on the use and implementation of tools such as queuing analysis, discrete event simulation, or system dynamics modeling.
- Engage with experts in geographical information systems to determine the optimal approach for developing geographic specific models so as to best serve the unique needs of particular populations throughout the province.
- Review whether all relevant factors have been identified and used in the models to predict future continuing care demand (for example predicted increases in the incidence of dementia).
- Develop and validate models using historical data where it is available.
- Make explicit the assumptions that underlie the prediction models and consider testing the predictions using different assumptions to gain understanding of the limits of the models that are being used.
- Develop capacity predictions that would take into account occupancy rates that are less than 100 per cent in continuing care.

APPENDICES

Appendix I: Terms of reference



HQCA Review of AHS Policy *Continuing Care Waitlist: First Available Appropriate Living Option*

Terms of Reference

Purpose

Pursuant to section 3 (1), 6 (2), 15 (2), 16 (1) of the *Health Quality Council of Alberta Act*, the Health Quality Council of Alberta (HQCA) will conduct an independent review of the quality and patient safety implications of the AHS policy *Continuing Care Waitlist: First Available Appropriate Living Option* (FAALO).

Objective

The HQCA will conduct a review and make recommendations on the quality and safety implications of the AHS policy *Continuing Care Waitlist: First Available Appropriate Living Option*. The process of the review will include but is not limited to:

- FAALO policies in the legacy health regions in Alberta
- Current but not operational AHS FAALO policy
- Similar FAALO policies in Canada and elsewhere
- Client¹ experiences with FAALO policies in Alberta
- The impact of FAALO policies on the performance of the continuing care system and the broader Alberta health system

Stakeholders

Stakeholders that may be engaged in the review process include but are not limited to:

- Alberta Health Services
- Alberta Health
- Continuing care (supportive living, facility living)
- Long term care providers
- Patients, clients and families
- Physicians and other health care providers

Deliverables and Timelines

- A full report of the findings with recommendations will be presented to the Alberta Health Services Chief Executive Officer by January 31st, 2014, and will be made public.
- Prompt reporting of any factual irregularities that may immediately affect patient safety will be provided to Dr. Verna Yiu, EVP/CMO, Quality and Medical Affairs, Alberta Health Services.

¹ Client refers to a client or resident

Regular updates on the status of the review will be provided by the Health Quality Council of Alberta to Alberta Health Services.

Approved by:



John W. F. Cowell M.Sc., MD, CCFP, FRCP
Chief Executive Officer
Health Quality Council of Alberta



Dr. Chris Eagle MD, MBA, FRCPC
President and Chief Executive Officer
Alberta Health Services

July 30, 2013
Date

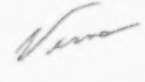
3 September, 2013
Date

Appendix II: Terms of reference – extension letter



January 16, 2014

Verna Yiu,
VP Quality & Chief Medical Officer
Alberta Health Services
Seventh Street Plaza, North Tower, 14-030
10030 - 107 St.
Edmonton, AB T5J 3E4

Dear Dr. Yiu 

Re: Terms of Reference (TOR) for the HQCA Review of AHS Policy Continuing Care Waitlist:
First Available Appropriate Living Option

Whereas the HQCA and AHS agreed to the Terms of Reference (TOR) for the HQCA Review of AHS Policy Continuing Care Waitlist: First Available Appropriate Living Option signed July 30, 2013 and September 3, 2013 respectively; the HQCA and AHS agree to amend the TOR by extending the date for the final report from January 31, 2014 to February 28, 2014. In all other aspects the TOR remain unchanged.

Thank you for your consideration and agreement to this extension

Sincerely,



Patricia Pelton
Acting CEO, HQCA
Chair, HQCA Quality Assurance Committee



Appendix III: Environmental scan of first available living option policies

Area	Prioritization and management of access to continuing care living options	Distance / Other Criteria	Preferred facility selection criteria
British Columbia	The provincial "Long-Term Service Needs Determination" policy, effective October 2012 requires a client to accept the first appropriate bed where the client's preferred facility or location.¹ The policy is facilitated by the five regional health authorities; clients with the highest need and urgency have priority for the first available.^{2,3} Since clients in hospital are often considered to have the highest needs, clients waiting in the community often are admitted to hospital in crisis before they are able to residential bed.⁴ Patients may request a transfer to a preferred care facility when a bed becomes available after they are admitted to residential care.^{2,5,6} Clients were expected to move or agree to move to the first available bed within 48 hours or their name would either be dropped to the bottom of the list or removed from the list but after the release of the February 2012 Ombudsperson's report, some health authorities giving more consideration to the appropriateness of the bed.^{2,3,4,5,6,7}	As of 2012, factors that may be considered include distance from the person's family and friends, location of a spouse in another facility and suitability from a clinical perspective.^{2,3,4,5,6}	The selection practice varies by health region. Following are examples of criteria clients/patients are given when choosing their preferred facility: ▪ Fraser Health Authority and Vancouver Island Health Authority: preferred geographic area and one preferred facility; ▪ Northern Health Authority: two preferred facilities if a community has more than one facility; ▪ Interior Health Authority: Okanagan - up to three preferred facilities, outside the Okanagan - one preferred facility; ▪ Vancouver Coastal Health Authority: one preferred facility.⁷
Saskatchewan	The assessment and prioritizing (on basis of assessed need) of individuals for placement in special-care homes is the responsibility of the health region.² There are currently 12 health regions.⁸ "Most Regional Health Authorities offer the person with the greatest need and living at the greatest risk the first available bed with the option to transfer to the facility of their choice when a bed becomes available there."⁹ Regina Qu'Appelle Health Region: Patients in hospital must accept the first available bed but can transfer to another facility later when space is available: these patient names will be at the top of the waiting list.² Saskatoon: Patients are placed through a single entry system with admission to the first available bed through Client Patient Access Services (CPAS) in the Saskatoon area and through a Home Care Client Coordinator in the rural areas. Transfers to another special care home can be requested after admission.²	As of November, 2013 five of the regions have no distance limits; Saskatoon has a maximum of 75 kilometres limit and Regina is considering a 150 kilometres distance limit.¹⁰	

Manitoba	Long term care facilities are referred to as Personal Care Home (PCH). Manitoba Health is responsible for setting fees and inspecting PCHs.¹¹ Admissions to long term care facilities are managed by the 5 Regional Health Authorities (RHA). A regional panel approves the application for a PCH. Clients waiting a PCH must accept the first bed that becomes available. After accepting the first available bed, patients may request to be placed on their preferred home's waiting list for transfer there.^{2,12} Winnipeg has a separate Long Term Care Access Centre within the RHA to manage admissions into long term care facilities.² An Expanded Long-term Care Placement Tool includes a decision tree analysis to help identify placements for supportive housing and or personal care homes.^{11,13}	A committee reviews all applicants on the waiting list to decide who will be offered the bed based on factors such as the length of time an applicant has been on a waiting list, urgency of care needs, risk factors, and ability of the facility to meet the care needs of the applicant.¹¹	
Ontario	Ontario's Admission to Long Term Care policy (based on the Long Term Care Act of 2007 and the Health Consent Act) allows individuals who have been identified as no longer requiring hospital care (ALC designation) to wait in hospital until a continuing care site of their choice becomes available.¹⁴ This policy states that while patients "can be encouraged, they cannot be required to choose a specific number of LTC homes or homes with short waiting lists. In addition, they cannot be required to accept a first available bed that is not one of the person's choices. These consumer rights have been a well-established part of the placement co-ordination system since 1993."¹⁵ This policy also requires that consent from a patient must be obtained; the patient cannot be forced into a nursing home.^{15,16,17} The province's 14 Community Care Access Centres (CCACs) determine eligibility for admission, prioritize eligible individuals on LTC homes' wait lists and arrange placement.^{15,16,17} Patients in hospital or those with the highest health care needs are given first priority to a nursing home bed. If they are classified into a crisis category they are moved to the top of the waiting list for the home of their choice and the CCAC will discuss with the person whether they will accept a different facility but they cannot be required to accept it.¹⁸		The selection practice varies by health region. Following are examples of criteria patients are given when choosing their preferred facility: ▪ CCAC – North Bay: up to five (5) long-term care homes, in order of preference.¹⁹ ▪ Ottawa CCAC - 1 preferred choice and 2 short list choices.²⁰ ▪ Central West CCAC – as many as five²¹
Quebec	Admissions to Long term care is managed by Local Community Service Centres (CLSC).²² Clients or their family or friends can make a request for admission into a CHSLD (centre hosting and long-term care) by contacting their local CLSC hospitals. The patient will have a medical evaluation and an assessment of physical & mental capacities by CLSC staff.²²		

New Brunswick	Nursing home facilities are approved and monitored by the Department of Health. The Department of Social Development assesses patients and approves applications for placements in nursing homes. Nursing homes are under the direction of the Nursing Home Services branch.²³ A Single Entry Point Committee determines eligibility for a nursing home bed.²⁴ Patients waiting for a nursing home bed in hospital must accept the first bed offer based on the First Available Bed Policy. Patients may request a transfer to their preferred home once admitted in the first available bed.^{2,24}	Patient names will be added to the waiting list of all nursing homes within a 100 km radius of the municipality that they live in. They can refuse one bed offer but if they refuse a second bed offer, their name will be removed from the waiting list. Hospitals may charge the patient for their room if they refuse a bed offer. They can refuse any bed offer, without penalty, if they do not speak the official language of the home.^{24,25}	Patients are asked to choose identify 3 preferred choices.^{2,24}
Nova Scotia	The Department of Health is responsible for the assessments for care and for finances. Classification Officers from the Department of Health and Wellness, Continuing Care Branch have the authority for approving or declining applications for admission to Department of Health and Wellness long term care facilities.²⁶ The wait list is managed according to three priority rankings.²⁶ "The guiding principle of the First Available Bed Provision is that the care needs of the applicant shall be addressed first and his or her placement preferences shall be pursued second."²⁶	Names of hospital patients assessed as eligible will be placed on the wait lists of all long term care facilities that are suitable to meet the applicant's care needs and that are within 100 km (driving distance) of the community of their choice if a suitable bed is not available in their preferred home.^{26,27} When a patient accepts the first available bed, they are able to maintain their position on the wait list. If they decline the first available bed, they are removed from all wait lists but may reapply later.²⁷	
Prince Edward Island	If a patient is in hospital, they are required to take the first available bed; they may later request a transfer to the home/manor they prefer. They will maintain priority on the waiting list.^{2,28} An assessment using a Senior Assessment Screening Tool and a priority needs process is completed by committees in each region with representatives from hospitals and Home Care, Housing and Long-term Care programs to approve applications to long-term nursing care facilities.^{28,29}		Patients living in the community may provide a list of homes they prefer. They can turn down the first bed offer, but if they reject a bed a second time they will be removed from the waiting list.^{2,28}

Newfoundland & Labrador	Admissions to residential long term care facilities are managed by the Regional Health Authority (RHA) through a provincial policy.³⁰ Labrador Grenfell Health does not have a First available bed policy that allows transfer between all facilities where an empty bed is available because of the geographic distances between sites. Eastern Health has a first available bed policy that applies to all ALC patients and all personal care home residents who can no longer safely reside in that level of care setting. Eastern Health does not have a regional FAB policy as of yet that allows transfer between all facilities where an empty bed is located. Eastern Health admits at least half of all LTC residents directly from hospital through a FAB policy and as such there is a large internal transfer list of residents who wish to transfer to home of choice. Within Labrador Grenfell Health, access and approval for Long Term care are managed through a single Entry process. A Regional Assessment and Placement Coordinator oversees the Regional Assessment and Placement Single Entry program. Local Assessment and Placement teams at each respective site are responsible for paneling all request and management of their waitlist. Access is prioritized based on greatest need and then greatest wait time. Some LTCF have preferential access policy for clergy and/or cottage tenants that are enabled through a Memorandum of Agreement. Within Central Health, access and approvals for long term care is managed through the Single Entry Assessment and Placement Process. Within Central Health, there is a "First Available Bed policy" that is consistently applied. Ethics review has been completed. Long Term Care Homes provide the highest level of nursing care and allied services to level 3 and 4 residents. Personal Care Homes provide assistance to level 1 and 2 residents. A community based Protective Community Residence provides specialized care and accommodations for individuals with mild to moderate dementia. Affordable Housing Cottages provide maintenance, snow clearing and lawn care to persons who can live independently or with home supports. Clients who remain in their own home can access Home Support services including personnel care, housekeeping and respite services.	In some rural areas of Eastern Health there are geographic distances applied to allow transfer to LTCF within a defined area. Policy is in place to support offering placement to persons with highest priority.	Patients are asked to choose 3 nursing homes that they prefer.³¹
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Northwest Territories	At this point most people accept the LTC bed offered so a FAALO policy is not required. The Government of the Northwest Territories, Department of Health and Social Services, Territorial Admissions Committee (TAC) provides a territory wide process for the application and admission to NWT long term care facilities.	TAC oversees a single co-ordinated, prioritized placement list and their goal is to place applicants as close to home as possible.	As per the TAC policy, if someone accepts a bed that is not their preferred facility they have priority for the next available bed in their preferred facility.
Yukon	There are four continuing care facilities in the Yukon; three are located in Whitehorse and one in Dawson City.³² Assessment, wait lists and admissions into a nursing home are managed by the Admission/Assessment Coordinator at the Continuing Care branch of the Department of Health and Social Services.³² Unable to confirm if FAALO policy existed.		
Nunavut	Nunavut has three health regions under the Department of Health and Social Services.³³ Assessment, wait lists and admissions into a nursing home are managed by the regional health authorities.³⁴ Unable to confirm if FAALO policy existed.		

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Appendix IV: Literature review

Report for the Health Quality Council of Alberta

Title: Continuing Care Waitlist Management Policies:
A Review and Summary of the Recent Literature

October 2013

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EXECUTIVE SUMMARY

Introduction

From the client perspective, selection of a long-term care (LTC) facility is influenced by a number of factors. Individual client needs (e.g., the need for specialized care) and personal preferences (e.g., proximity to family, desire to be placed along with a spouse) are all important considerations. Across Canada, wait times for LTC placement, particularly at a client's preferred location, can be long. Individuals may wait in the community or in other settings, such as in acute care beds, where the level and type of care maybe not be an appropriate fit for client needs or from the health care system perspective, where shortages of hospital beds is an ongoing concern. Long-term care waitlist management policies (such as First Available Appropriate Living Option or FAALO) have been implemented in an attempt to facilitate timelier placement into LTC. The overall objective of literature review was to summarize the recent literature related to the impact of waiting for LTC placement and of waitlist management policies on clients and the health care system.

Methods

This literature review was conducted in accordance with a research protocol that was developed a priori. Database and grey literature searches from 2008 and onwards were conducted to identify literature relevant to six specific research questions related to the impact of waiting for long-term care placement, first available bed policies and similar waitlist management policies on the client and healthcare system. Research reports that met the selection criteria were summarized narratively and supplemented with a summary of key information from articles from the secondary literature for each question.

Results

In total, 15 primary qualitative or quantitative research studies or systematic reviews relevant to one of the six research questions were identified. Two additional opinion pieces were included that discussed ethical considerations related to LTC placement policies or patients with delayed discharge.

Impact of waiting in acute care or community for LTC placement on client health

Qualitative and quantitative studies suggest that waiting for LTC placement is associated with a mental health burden, as evidenced through reports of anxiety and high rates of anxiolytic and psychotropic drug use in clients awaiting placement. Further, psychiatric symptoms (crying, sadness) were also directly observed. One quantitative study followed hospital patients waiting for long-term care placement over a four month period and found that the impact on HRQL was inconclusive. While

difficulties with physical and cognitive function were observed in alternate level of care patients waiting in hospital for LTC placement, the time course of decline could not be ascertained due to the design of the studies.

Impact of initial LTC placement on client health

Evidence from one large cohort study suggests that there is an increased risk of emergency department transfer in the first 30 days of LTC placement. However, the underlying reason, cause or diagnosis related to these transfers was not available. A small study of nutritional status following LTC placement identified changes in hemoglobin and poor eating in the six months post LTC admission. Weight loss also occurred, but the change was statistically nonsignificant. Qualitative studies identified feelings of loss related to different aspects of life during the transition to LTC. Sadness and distress were also reported during the transitional period. At the same time, some informants reported that there was an increased opportunity for socializing in LTC relative to their previous location.

Effect of moving a client between locations in a short period of time

No studies were identified from the database searches or the grey literature that directly explored the incremental effects of multiple transfers on the health of clients. One systematic review of forced relocation between nursing homes found that the experience was stressful and had an adverse effect on some health outcomes. However, the impact on mortality was variable. The review authors suggested that carefully planned relocation may reduce the risk of adverse outcomes with forced relocation.

Ethical issues in LTC waitlist management policies

Justice or fairness, autonomy or choice, and equitable resource allocation were identified as ethical considerations when developing policies that allocate LTC beds.

Evidence of the effectiveness of FAALO or similar policies on patient flow

The Community Care Act was implemented in the United Kingdom to help address issues related to delayed discharges from the acute care setting to LTC. One research study and one literature review identified reductions in delayed transfers and shortened average hospital stays following the implementation of the Act; however, there was also an increase in readmission rates over the same time period, which was concerning. Further, the reduction in delayed discharge may have pre-dated implementation of the Act.

Legal challenges to FAALO policies in Canada

Following the death of an elderly woman within 48 hours of placement at a distant LTC facility and the death of her spouse two weeks later, a report to British Columbia's Ministry of Health recommended that the first available bed policy be reviewed to better clarify criteria for decision-making under its application. No legal action pursuant to these events was identified. In Ontario, the Ministry of Health

has clarified that charging of fees while waiting for LTC placement in hospital in excess of the per diem rate for basic accommodation in LTC is not permitted. Charging of such fees was been challenged legally and it was found to be not permissible. The Ministry has further clarified that the choice of LTC facility is at the discretion of the client or surrogate decision-maker. Current legislation in Ontario prohibits the use of first available bed policies.

Conclusions

The recent evidence relating to the effects of waiting for LTC placement, the initial impact of placement on client health and the effect of LTC waitlist policies on patient flow in other areas of the healthcare system was limited. The identified evidence suggested that the uncertainty of waiting for placement was a source of anxiety for clients and that the initial placement was associated with feelings of loss. Reductions in delayed discharge and length of stay, but increased readmission rates have been observed following the implementation of legislation intended to reduce delayed discharge. No literature was identified that directly evaluated the impact of multiple moves on the health of LTC clients, so no conclusions can be made with respect to this research question.

Abbreviations

ADLs	Activities of Daily Living
CCAC	Community Care Access Centres
CI	Confidence Interval
ED	Emergency Department
FAALO	First Available Appropriate Living Option
HRQL	Health related quality of life
ICU	Intensive care unit
LIHN	Local Health Integration Networks
LTC	Long-term care
NH	Nursing Home
NHS	National Health Service

Definitions

Alternate Level of Care Patient: A patient who occupies a bed in a hospital but does not require the intensity of resources or services provided in this care setting (Acute, Complex Continuing Care, Mental Health or Rehabilitation).

Delayed Discharge: A hospital inpatient who has been judged clinically ready for discharge by the responsible clinician but continues to occupy a bed beyond the ready for discharge date.

First Available Appropriate Living Options (FAALO): A policy that required individuals waiting for long-term care placement in hospital to accept the first available bed that became available within 100 kilometres of their current location on a temporary basis while waiting for their preferred location.

Introduction

The decision to transition into long-term care (LTC) is complex, with many factors to consider. For some, the decision is made while still living in the community with formal and informal support from family or paid caregivers. For others, the need for LTC placement can arise suddenly, following a major health event that makes it challenging to return to the previous level of functioning and independence. Once the need for LTC placement is apparent, there is usually a waiting period, which can be affected by a number of factors.¹ The level of care that the client requires, special needs related to medical and psychiatric comorbidities, and rehabilitation needs can all affect placement time. Nonmedical factors such as the desire to be at a location near to family and friends or same location as a spouse, also affects placement time.^{1,2}

Individuals may wait for LTC placement in the community or in other settings, such as in acute care. Extended waiting periods for LTC placement, particularly in acute care settings where resources are scarce, raises a number of concerns. There are concerns that having hospital beds occupied by clients who no longer require acute care contributes to the shortage of hospital beds, effects efficiency in other healthcare resource categories, and places clients at risk of iatrogenesis.^{2,3}

Policies have been proposed to help to better manage LTC waitlists and reduce the time waiting in community and in acute care settings where care may be suboptimal for any number of reasons. One such a policy is referred to the First Available Appropriate Living Option (FAALO) which can exist in different formats, but mandates that clients who are waiting in acute care settings accept the first bed that becomes available within a geographic location (for example, within 100 km of where they live), regardless of whether it is at one of their preferred locations. The client then remains on the wait list for his or her preferred location, while occupying a LTC bed. Theoretically, this allows the client to wait where the level of care is more aligned with their health care needs. However, operationalizing such policy can create challenges with being at a distance from family and spouses. This scenario also creates the need for multiple moves (from the acute care setting to the first available LTC bed and then between LTC facilities).

The overall objective of literature review was to summarize the recent literature related to the impact of waiting for LTC placement and of waitlist management policies on clients and the health care system.

Project methods

This literature review was conducted in accordance with a research protocol that was developed a priori.

Research questions

The following research questions were generated in consideration of the overall objective for this literature review.

1. What is the impact on the health of clients waiting in acute care and in the community for LTC placement?
2. What is the impact on the health of a client when the client first moves from community or acute care to long-term care?
3. What is the incremental effect of moving a client from one location (residence) to another location (residence) more than once in a short period of time (< 3 months or <6 months)?
4.
 - a. What are the studies of ethical issues that come into play when developing a LTC wait list management policy (e.g. justice, choice, resource allocation)?
 - b. Are there specific ethical issues that arise when the policy 'insists clients accept the first available bed' that is not one of their preferred options and may be up to 100 km from their current location?
5. Is there evidence of the effectiveness of FAALO or similar policies on patient flow in acute or long-term care?
6.
 - a. Have there been legal challenges to FAALO policies in Canada?
 - b. If so, what is the nature of those challenges?

Searches of electronic databases

Search terms for each question were developed by the researcher and reviewed by the team for completeness. Additional search terms were added based upon the team's input. The search terms were developed to reflect the population, intervention, comparator and outcomes of interest and study designs where appropriate. The search terms are found in Appendix 1.

Database searches were conducted on PubMed In Process, Embase, OVID Medline, CINAHL, OVID Healthstar, PsychINFO, Sociological Abstracts, The Cochrane Library (2013, Issue 9), University of York Centre for Reviews and Dissemination (CRD), Database of Abstracts of Reviews of Effects (DARE), EBM Reviews – HTA, and NHS Economic Evaluation Database (NHSEED). The search time frame was from January 2008 to September 30, 2013. The search results were further restricted to English language. The grey literature search included the sites of Canadian and major international health technology agencies,

as well as a focused Internet search of provincial/territorial government websites and other relevant international websites, such as the National Health Service. CADTH's *"Grey matters: a practical search tool for evidence-based medicine"* was used to guide the grey literature search. Reference lists of included literature were also reviewed to identify potentially relevant literature. Potentially relevant content was also identified by a content expert in geriatrics.

Literature selection

The titles and abstracts of citations retrieved from the database searches were reviewed and potentially relevant reports were retrieved for full-text screening. Full-text reports were then screened for inclusion based upon pre-determined selection criteria. Literature was selected for inclusion if the selection criteria were met for any of the six research questions (Appendix 2). Other potentially relevant reports identified through the grey literature search and hand-searching also underwent full-text screening and were included if the selection criteria were met. A content expert in geriatrics then reviewed the list of included studies to identify any known literature that was not captured by the database and grey literature searches. This literature also underwent screening according to the selection criteria.

Data extraction and summary

Relevant evidence from the included reports was extracted into data tables and summarized narratively. For primary research studies (both qualitative and quantitative) data extraction included a description of the study design, research methodology, and key findings. A critical appraisal of the research methodology of these studies was also conducted and key limitations were highlighted.

Results

Fifteen^{1,4-17} research reports were selected for inclusion into the literature review. Two opinion pieces related to Question 4 were also included.^{3,18} This information was supplemented with summaries of key information from additional articles or reports. Study characteristics, critical appraisal and findings are presented according to research question.

Question 1

What is the impact on the health of clients waiting in acute care and in the community for LTC placement?

Secondary sources

Literature suggests that waiting for LTC placement in an acute care facility has a negative impact on the health of the client.^{1,18-23} The potential for an accelerated rate of functional decline^{1,18} and loss of

independence^{1,18} while in hospital have been cited as physical concerns related to extended hospital stays in older adults. Other concerns related to prolonged hospitalization include falls, delirium, and pressure ulcers.⁸ A position statement from the Australian and New Zealand Society for Geriatric Medicine also suggests functional decline is common, with a substantial proportion of older adults (30% to 55%) experiencing a decline in ability to perform activities of daily living (ADLs) and an even greater proportion (65%) experiencing decline in mobility.²³ This, in part, was thought to relate to a loss of motivation once LTC placement is imminent.²³ The Australian and New Zealand Society for Geriatric Medicine further state that this decline in function contributes to the inability to return to independent living and that "An older person whose discharge is delayed should be cared for in an environment with adequate resources to maintain function and to facilitate discharge to the community should there be a change in the patient's condition or in availability of carer support."²³ They stress the need for making available interventions that restore and preserve function and independence while waiting in hospital.²³

Of further concern, high bed occupancy rates¹⁹⁻²² and extended lengths of stay have been associated with nosocomial infections.²⁴⁻²⁶ Thus, the risk of developing a nosocomial infection while waiting in an acute care setting for LTC placement is a potential risk.

In addition to the physical functional concerns related to extended hospital stays and delayed discharge, concerns about decline in cognitive function, social isolation and mental health have been highlighted in the literature.^{1,18,23} Anxiety, depression and loss of morale are cited as potential effects of extended hospitalization or delayed discharge.²³

In summary, it has been suggested that physical and cognitive function may potentially decline while waiting in hospital for LTC placement and mental health may be adversely affected, as well, during the waiting period.

Research reports

Five primary studies from the database searches^{1,5-8} and one report from the grey literature⁹ were identified that provided evidence regarding the health impact of waiting in acute care or in the community for LTC placement and met the inclusion criteria for question one of this literature review. The design and study population characteristics of these studies are summarized in Table 1.

Two of the included studies were set in Ontario,^{1,8} one in Alberta,⁹ one in the United Kingdom,⁶ one in Australia⁵ and one in Norway.⁷ Two of the six studies employed qualitative research methodologies,^{6,9} while the other four used various quantitative research designs.^{1,5,7,8} Two of the four quantitative studies were retrospective in design.^{1,8} The other two used prospective designs, one of which was a single group follow-up study,⁵ while the other compared elderly waiting in the community for nursing home placement to those already residing in nursing homes.⁷

Table 1: Characteristics of Included Studies (Question 1)

Author, Year of Publication, Setting	Objective	Study Design and Sample Description	Demographic Characteristics
Costa et al., 2012 ¹ Acute care hospital located in a large health region in Southern Ontario	To identify and describe ALC patients that account for a substantial portion of total acute hospital ALC bed days.	Retrospective cross-sectional study of a single cohort of patients. All hospital discharges between April 1, 2009 and March 31 st , 2011 with an alternate level of care designation. Patients waiting for nursing home placement were identified through medical records (n=1488).	ALC patients waiting for NH placement Mean age: 81.2 years (SD not reported) Female: 57.6%
Costa et al, 2010 ⁸ Ontario, Canada	To compare ALC patients waiting for LTC in acute and complex hospitals to home care clients.	Case control study Cases: 13,915 ALC patients waiting for LTC admission identified through the RAI-HC database from January 2007 to September 2008. Controls: 113,046 long-stay home care clients over the age of 65 identified through the RAI-HC database from January 2007 to September 2008.	Mean Age $\pm$ SD - years ALC: 83.0 $\pm$ 0.1 Home care: 82.1 $\pm$ 0.06 Female ALC: 61.5% Home care: 68%
Giles et al, 2009 ⁵ Three public hospitals in Adelaide, Australia	To assess HRQL and health outcomes in older people awaiting transfer to residential aged care.	Single group prospective study with comparison of baseline and 4 month outcomes. 320 patients awaiting a residential aged care bed who consented to participate. Part of a larger RCT ²⁷ that compared outcomes of	Mean $\pm$ SD Age - years 82.9 $\pm$ 7.9 Female: 50%

Author, Year of Publication, Setting	Objective	Study Design and Sample Description	Demographic Characteristics
		patients randomized to waiting for placement in hospital or in a transitional care facility.	
Fjelltn et al, 2009 ⁷ A single municipality in Norway	To compare functional levels of elderly awaiting nursing home placement and nursing home residents.	Prospective comparative study of two groups: Clients over the age of 67 awaiting NH placement in the community with home health care (n=36) Clients over the age of 67 residing in a single nursing home (n=47)	Mean $\pm$ SD Age - years Waiting for NH: 84.6 $\pm$ 8.4 NH: 83.1 $\pm$ 6.3 Female Waiting for NH: 61.1% NH: 68.1%
Kydd A, 2008 ⁶ A single hospital ward in the United Kingdom	To explore what life was like for elderly people with delayed discharge	Qualitative study of 14 patients with a delayed discharge status that were waiting for long-term care placement.	No demographics presented
Hopper T, 2008 ⁹ Two health regions in Alberta with clients waiting in the community and in hospital for LTC placement.	To determine factors that influence continuity of care for older adults requiring continuing care services.	Case study of two health regions involving quantitative analysis of databases (not relevant to Question 1 of this report) and qualitative analysis of interviews with clients who were waitlisted and their families.	Qualitative sample Female: 85% Age not reported.

ALC Alternate Level of Care; HRQL Health-Related Quality of Life; LTC Long-term Care; NH Nursing Home; RCT Randomized Controlled Trial; SD Standard Deviation

Quantitative Studies

Key study findings, limitations and conclusions of the primary research studies identified to address Question 1 are summarized in Table 2. Costa et al, 2012¹ used information from databases to describe

the characteristics of alternate level of care (ALC) clients who were waiting for LTC placement (clients who remain in hospital when acute care services are no longer medically necessary due to delay in discharge) (Table 2). They found that clients who were waiting for nursing home placement comprised 8.8% of ALC clients, but accounted for 41.5% of alternate level of ALC days. On average, these clients waited 82.0 ± 2.4 days for placement after being designated ALC. Cognitive impairment, functional impairment, psychotropic medication use, dementias, behavioral problems and psychiatric conditions were common in ALC patients who were waiting for nursing home placement (Table 1). A number of these factors were associated with longer ALC stays (abusive behavior, psychiatric diagnosis, use of antidepressants, anxiolytics, and antipsychotics). Due to the design of this study (Table 1 - Limitations), the time course of events (e.g., whether cognition, function or mood declined over the course of hospitalization) could not be directly assessed. However, it was apparent that those clients waiting in hospital for LTC placement had impairments in these areas.

Costa et al, 2010⁸ compared ALC clients waiting for LTC placement in hospital to home care clients in the community using information from a number of databases (Table 2). Higher prevalence of functional and cognitive impairments, psychiatric issues (depression and behavioral disturbances), falls and unstable health were found in ALC clients relative to home care clients. The most commonly documented needs of ALC clients included improving or preventing functional decline in ADLs, preventing falls, managing urinary incontinence, mood and pain control. Due to the retrospective design of this study, the identified characteristics and needs of ALC clients cannot be considered "emergent" or attributed to waiting for LTC placement.

Fjelltn et al, 2009⁷ compared clients who were waiting for nursing home placement in the community to those who were already residing in LTC (Table 2). They found that most measures of cognition and function showed greater impairment for clients already residing in nursing home. Behavioral disturbances were also more prevalent in nursing home residents. However, clients who were waiting for nursing home placement had a higher prevalence of some psychiatric symptoms (sadness, crying, being fearful or suspicious).

Only one identified study evaluated change over time while waiting in hospital for LTC placement. Giles et al, 2009⁵ evaluated health related quality of life (HRQL) at baseline and after four months of waiting for LTC placement (Table 2). They found that HRQL was extremely poor (relative to population norms) at both time points. HRQL improved from baseline to the four month follow-up; however, the change was statistically nonsignificant and the clinical importance of the change was unclear. Further, interpretation of the data was obscured by a relatively high mortality rate over the follow-up period.

Qualitative Studies

Two studies reported qualitative findings in relation to waiting for LTC placement (Table 2).^{6,9} Kydd, 2008⁶ collected data from a United Kingdom-based group of clients who were waiting for LTC placement in hospital. Key themes suggested that clients waiting for LTC placement experienced anxiety, boredom and social isolation. Clients desired placement in a care home that was easy for their relatives to visit. Similarly, data from qualitative interviews in an Alberta-based sample (Hopper 2008)⁹ identified the importance of proximity to family and anxiety in relation to waiting (Table 2).

Summary

Qualitative and quantitative studies suggest that waiting for LTC placement is associated with a mental health burden. Anxiety was a common theme in two qualitative studies^{6,9} and cross-sectional data on medication use¹ (high rates of anxiolytic and psychotropic medication use) support this observation. Further, psychiatric symptoms (crying, sadness) were directly observed in a study of clients waiting in the community for LTC placement.⁷ Only one quantitative study followed patients waiting for long-term care placement over time (a four month period) and found that the impact on HRQL was inconclusive. While difficulties with physical function and cognitive function were observed in ALC patients waiting in hospital for LTC placement, the time course of decline could not be ascertained due to the design of the studies.^{1,8}

Table 2: Key Findings, Critical Appraisal Points and Conclusions for Included Studies (Question 1)

Author, Year of Publication, Setting	Key Findings	Key Critical Appraisal Points	Authors' Conclusions
Costa et al., 2012 ¹ Acute care hospital located in a large health region in Southern Ontario	8.8% of ALC patients were waiting for NH placement. ALC patients waiting for NH placement accounted for 41.5% of ALC days. Mean ALC length of stay for patients waiting for NH placement: 82.0 ± 2.4 days. Prevalence of Comorbidities in ALC Patients Waiting for NH Placement: • Cognitive impairment - 50% • ADL Impairment - > 75% • Signs of depression - 12% • Delirium in last 90 days - 25% • Behavior problems - 25% • Psychiatric conditions - 21% • Psychotropic medication use - 65% • AZD and other dementias - 49% Longer ALC lengths of stay for patients waiting NH placement with the following conditions: • Age categories less than 65 years of age and 65 to 74 years. • Psychiatric diagnosis • Abusive behavior • Receiving anxiolytics, antidepressants, and antipsychotics. • Male • Stroke • Morbidly obese	Cross-sectional study so cannot determine trends over time (e.g., if ability to perform ADLs or cognition declined while waiting for placement or were stable but impaired over course of hospitalization) Characteristics identified cannot be considered "emergent" or attributed to waiting for NH placement due to cross-sectional design. Cannot make causal inferences or attributions (e.g., if waiting for NH placement in hospital caused depression). Lack of comparison group or control. No description of available resources such as programming, geriatric assessment and rehabilitation available to ALC	No conclusions were made specific to the health impact of waiting for LTC placement in an acute care facility ALC patients waiting for LTC placement contribute to a substantial proportion of non-medical hospital days.

Author, Year of Publication, Setting	Key Findings	Key Critical Appraisal Points	Authors' Conclusions
		patients. Data from a single health region and a single point in time, so generalizability to other geographical areas or time periods unclear.	
Costa et al, 2010 ^a Ontario, Canada	Prevalence of Key Comorbidities* Moderate to severe cognitive impairment ALC: 36.3% Home care: 11% Delirium ALC: 8.6% Home care: 1.9% Diminished communication skills ALC: 26% Home care: 8.9% Depressive symptoms ALC: 17.5% Home care: 13.2% Behavioral disturbances ALC: 19% Home care: 6.3% Dependent Functional Status	Characteristics identified cannot be considered "emergent" or attributed to waiting for NH placement due to retrospective design (i.e. cannot determine if the identified characteristics were causes for or consequences of prolonged ALC hospital stay. Cannot make causal inferences or attributions given the study design No description of available resources such as programming, geriatric assessment and rehabilitation available to ALC patients and home care clients. The availability of such	Many ALC clients waiting LTC placement require targeted services at a higher level of intensity than home care clients. ALC patients waiting for LTC have complex medical and psychosocial needs.

Author, Year of Publication, Setting	Key Findings	Key Critical Appraisal Points	Authors' Conclusions
	ALC: 23.9% Home care: 2.8% 2 or More Falls in Past 90 days ALC: 15.7% Home care: 6.7% Health instability ALC: 27.5% Home care: 10.3% Frequency of comorbidities was similar between groups, but the proportion of clients with complex needs was greater in the ALC group (52.4% versus 30.0%) Most common needs of ALC patients waiting LTC admission included: • Improving or preventing functional decline in ADLs • Falls • Urinary incontinence • Mood • Pain control	resources is a potential confounder to any comparisons between groups. No adjustment or control for potential confounding factors. Data from a single province and captured over a specific time period, so generalizability to other geographical areas or time periods unclear. Average duration of ALC hospital stay was not reported which makes generalizability less clear.	
Giles et al, 2009⁵ Three public hospitals in Adelaide, Australia	AQoL (Measure of HRQL) • Extremely poor HRQL at baseline (median 0.02, 95% CI: -0.01 to 0.04) and 4 month follow-up (median 0.05, 95% CI: 0.03 to 0.06). • Population norm of AQoL for Australians aged 70 and over is 0.73 • Poorest HRQL was on the independent living domain • Social relationships showed	Generalizability to other countries or regions unclear Mixture of proxy and self-reported HRQL data, which can impact the ability to interpret the data	There is a need for high level coordination of care for patients waiting in hospital for LTC placement. Rehabilitation and therapy should occur in the hospital setting

Author, Year of Publication, Setting	Key Findings	Key Critical Appraisal Points	Authors' Conclusions
	intermediate scores Change from baseline to the 4 month follow-up was statistically nonsignificant (median improvement of 0.01; 95% CI:0.00 to 0.01; p=0.17)	High mortality rate, so a significant number of clients had data imputed Relatively short duration of follow-up (4 months). Limited outcomes reported (a single, generic measure of HRQL), which might not capture all important dimensions of HRQL No description of available resources such as programming, geriatric assessment and rehabilitation available	while waiting.
Fjelltn et al, 2009⁷ A single municipality in Norway	Motor function was generally worse for clients residing in nursing homes, although statistical differences were only observed for 2 of 7 functions. - Able to walk up and down stairs without assistance Awaiting NH Placement: 22.2% In NH: 6.4%; P=0.048 - Able to rise from a chair Awaiting NH Placement:	Of the clients asked to participate, 69% to 77% agreed and completed the required questionnaires. Given the rate of nonresponse, there is potential for selection of a biased sample. Differences in the populations and	Elderly awaiting nursing home placement had high rates of sadness and fearfulness. Their emotional needs may be important to address.

Author, Year of Publication, Setting	Key Findings	Key Critical Appraisal Points	Authors' Conclusions
	61.1% In NH: 39.1%; P=0.050 ADL Function and cognition were lower for NH residents Behavioral disturbances were more prevalent in the NH residents. Psychiatric symptoms (sadness, crying, being fearful, suspicious, and some behaviours) were more common in clients awaiting NH placement, but most differences were not statistically significant.	potential confounding factors were not controlled for. Collection of data on psychiatric symptoms was via nurse observation from home health care nurses or facility nurses, not through patient report of symptoms. Patients in the community were only observed for a few hours each day, so the prevalence of observed psychiatric symptoms could be underestimated. No adjustment for multiple statistical testing (over 50 tests performed), which inflates the risk of type 1 error considerably. The study was set in Norway and involved a small group of patients, which could limit the generalizability of the findings.	
Kydd A, 2008 ⁶	Relevant Themes: There was a great deal of anxiety	No rationale for participant selection	Staff should be aware of the stress and anxiety

Author, Year of Publication, Setting	Key Findings	Key Critical Appraisal Points	Authors' Conclusions
A single hospital ward in the United Kingdom	about moving to the NH. Patients had low-expectations for pain relief. There were Few friendships between patients as they knew that they would be moving on. Most clients wanted to be placed in a care home that was easiest for their relatives to visit. Boredom was a common complaint	or sample size was provided. The author did not provide a description of research methods. The recruitment strategy was unclear. The methods for data collection were not stated. The rigor of the data analysis is unclear since this was not described. Unclear if ethical standards were maintained.	that inpatients waiting for LTC placement have, knowing that they have to move on.
Hopper T, 2008⁹ Two health regions in Alberta with clients waiting in the community and in hospital.	Relevant Themes: Waiting was described as difficult, marked by uncertainty and confusion about how the waitlist worked. Waiting was a source of anxiety. The primary factor in choosing location was proximity to family or caregiver's work or home.	Qualitative methodology seemed appropriate for research question. Ethical standards appeared to be maintained. Used semi-structured interview guide and appropriate methods for transcribing and	No conclusions stated.

Author, Year of Publication, Setting	Key Findings	Key Critical Appraisal Points	Authors' Conclusions
		analyzing content. Were unable to sample purposively, as intended due low response. No clear rationale for sample size recruited. Statement of findings sufficiently clear.	

ADLs Activities of daily living; ALC Alternate Level of Care; AQoL Assessment of Quality of Life; AZD Alzheimer Disease; HRQL Health-Related Quality of Life; LTC Long-term Care; NH Nursing Home; RCT Randomized Controlled Trial; SD Standard Deviation

*Statistical significance for each comparison was not reported individually. The authors noted, however, that due to the large sample size, most differences did achieve statistical significant.

Question 2

What is the impact on the health of a client when the client first moves from community or acute care to long-term care?

Secondary sources

The literature on the transitioning to LTC from either the community or from an acute care setting has suggested that there may be both positive and negative outcomes following transitions. Loss of independence and the motivation to remain independent and decline in quality of life have been cited as consequences of LTC placement.¹⁴ Concern has been expressed over potential problems during the transition period such as medication errors and omissions, breaks in the continuity of care for chronic medical conditions and delays in follow-up for diagnostic tests.²⁸ The potential for a negative psychological reaction to placement has been described in the literature and referred to as 'relocation syndrome', 'relocation stress syndrome', or 'transfer trauma'.²⁹ This stress reaction can have negative physiological and psychological effects.²⁹ Cited psychological effects include feelings of sadness and loneliness, depressed mood, irritability, and confusion, and feeling helpless, misunderstood and

insecure.²⁹ Possible physiological effects include upset stomach, increased heart rate, disrupted eating habits, sleep disturbances, back pain and muscle spasm.²⁹

Research reports

Six primary studies¹⁰⁻¹⁵ from the database searches were identified that provided evidence regarding the impact of transitioning to LTC from community or acute care on the health of the clients and met the inclusion criteria for question two of this literature review. The design and study population characteristics of these studies are summarized in Table 3.

One of the included studies was set in Ontario,¹⁰ one in Manitoba,¹² three in the United States,¹³⁻¹⁵ and one in the United Kingdom.¹¹ Two of the six studies had quantitative research designs,^{10,12} while the other four studies used qualitative methodologies.^{11,13-15}

Table 3: Characteristics of Included Studies (Question 2)

Author, Year of Publication, Setting	Objective	Study Design and Sample Size	Demographic Characteristics
Brandburg et al, 2012 ¹⁵ Single nursing home in the United States	To identify strategies that older adults use to adapt to life in LTC	Qualitative study using grounded theory methodology. N=21 participants	Age Range: 65 to 93 years % Female: 81%
Gruneir et al, 2012 ¹⁰ 600 LTC facilities in Ontario	To study the effect of recent transitions on the risk of emergency department transfer among chronic LTC residents	Cohort study of 64,589 residents in total, 1913 of whom had been recently admitted to LTC (less than 30 days)	Age > 85 years: Less than 30 days in LTC: 38% Greater than 90 days in LTC: 46% % Female Less than 30 days in LTC: 65% Greater than 90 days in LTC: 73%
Fraher and Coffey, 2011 ¹¹ Multiple LTC facilities in the United Kingdom	To explore older people's experience with the decision to relocate to LTC and their early experiences post-relocation	Hermeneutic phenomenological qualitative study with 8 participants over the age of 65 who had been in nursing home less than 3 months. Participants were purposively selected.	Age > 65: 100% % Female: 75%
Sitter et al, 2011 ¹² Two personal care homes in Winnipeg, Manitoba.	To explore the effect of relocating to a personal care home on nutritional status and eating habits	Single group study (n=13) that evaluated anthropometric information and clinical and biochemical information at baseline (2 to 3 months following	Mean $\pm$ SD Age: 83.0 $\pm$ 9.8 % Female: 57%

Author, Year of Publication, Setting	Objective	Study Design and Sample Size	Demographic Characteristics
		relocation) and six to seven months following relocation	
Barredo et al, 2008 ¹⁴ Single LTC residence in the United States	To describe the process of and factors associated with losses connected to permanent LTC placement in the elderly	Qualitative study of a 5 participant convenience sample. Participants were in LTC less than 12 months.	Age range: 84 to 94 years % Female: 60%
Saunders et al, 2008 ¹³ Single long-term care, aging in place complex in the United States	To explore experience of 5 newly admitted residents to an assisted living facility	Qualitative exploratory study of clients who were newly admitted to the facility. 5 participant convenience sample.	Mean $\pm$ SD Age: 79.8 (Range 63 to 91) years Sex: Not reported

ALC Alternate Level of Care; LTC Long-term Care; NH Nursing Home; SD Standard Deviation

Quantitative studies

Key study findings, limitations and conclusions of the primary research studies identified to address Question 2 are summarized in Table 4. Gruneir et al, 2012¹⁰ evaluated the association between a recent transition to LTC and the risk of emergency department transfer using a cohort design (Table 4). The cohort consisted of a total 64,589 residents, 1913 of whom had been admitted to LTC in the previous 30 days. An increased risk of emergency department transfer was observed over a six month follow-up period. For the entire group of newly admitted LTC residents, the risk of an emergency department transfer was almost double that of residents who had been in LTC 90 days or longer (adjusted OR=1.9; 95% CI: 1.7 to 2.1). When considering those newly admitted residents who had a previous hospital stay prior to LTC admission, the risk of emergency department transfer was increased approximately 2.5 times (adjusted OR=2.5; 95% CI: 2.2 to 2.9) relative to those who had been in LTC 90 days or longer.

Sitter et al, 2011¹² evaluated the effect of relocating to LTC on nutritional status and eating habits in a sample of 13 residents over a six to seven month follow-up period (Table 4). A statistically nonsignificant weight loss was observed from baseline to follow-up (80.2 ± 23.3 kg vs 77.0 ± 20.1 kg, $p > 0.05$). Based on direct observation of meals, about one-half of participants consumed less than 50% of

Canada's Food Guide recommended servings of food. Average reductions in serum iron levels and mean corpuscular hemoglobin concentration were observed, while vitamin D levels increased ($p < 0.05$ for all). Related to this, average medication use increased, including the use of calcium, vitamin D and vitamin B12. Analgesic use also increased, as did the use of medications to control bowels. A decline in cognition, measured with the MMSE, was observed as well (baseline 28.0 ± 2.1 vs 24.6 ± 5.7 at follow-up; $p < 0.05$). Changes in mood and function were also assessed and found to be statistically nonsignificant and small in magnitude. The generalizability of the results of this study may be limited by its small sample size, which should be considered when interpreting the study's findings.

Qualitative studies

Four qualitative studies assessed the impact of relocation or transitioning to LTC from the perspective of the client.^{11,13-15} Similar themes were identified across the four studies (Table 4). Feelings of loss related to independence,^{14,15} privacy,^{11,15} relationships,¹⁴ control and decision-making,¹³ and activity¹⁴ were reported across the four studies. Sadness, sorrow, angst and distress were also key themes identified in the studies.^{11,13} Being placed in a location that was considered unsuitable to the client was one factor associated with feelings of distress.¹¹ One positive theme was noted in two studies: greater opportunity for socializing and social interaction.^{11,14}

Summary

Evidence from one large cohort study suggests that there is an increased risk of emergency department transfer in the first 30 days of LTC placement. However, the underlying reason, cause or diagnosis related to these transfers was not captured in the study. A small study of nutritional status following LTC placement identified weight loss (although not statistically significant), changes in hemoglobin and poor eating in the six months following LTC admission. Qualitative studies identified that feelings of loss related to different aspects of life were commonly reported during the transition to LTC. Sadness and distress were also reported during the transitional period. At the same time, some informants reported that there was an increased opportunity for socializing in LTC.

Table 4: Key Findings, Critical Appraisal Points and Conclusions for Included Studies (Question 2)

Author, Year of Publication, Setting	Key Findings	Key Critical Appraisal Points	Authors' Conclusions
Brandburg et al, 2012 ¹⁵ Single nursing home in the United States	Losses were a key theme relevant to Question 2. Loss of independence and loss of privacy with transition to LTC and had to look for strategies to cope.	Objective clear and consistent with the grounded theory approach. Sample was selected purposively with justification of the approach Sample size was determined by achieving saturation Data collection and analysis methods appeared to be rigorous Ethical standards appeared to be maintained. The relationship between the researcher and participants was not adequately considered or described. Key findings were clearly stated.	Interventions to support resiliency in the transition to LTC are needed.
Gruneir et al, 2012 ¹⁰ 600 LTC facilities in	Compared to longer-stay residents, newly admitted were 1.9 times more likely (adjusted OR=1.9; 95% CI: 1.7 to 2.1) to have an	Prospective research design of large sample size. Included province wide	Health care transitions from hospital to LTC are associated with an increase in emergency department use among

Author, Year of Publication, Setting	Key Findings	Key Critical Appraisal Points	Authors' Conclusions
Ontario	emergency department transfer over a 6 month follow-up compared to those who had been in long-term care 90 days or longer. Those who were newly admitted without a prior hospital stay were 1.6 times more likely (adjusted OR=1.6; 95% CI: 1.4 to 1.8) to have an emergency department transfer over a 6 month follow-up compared to those who had been in long-term care 90 days or longer. Those who were newly admitted with a prior hospital stay were 2.5 times more likely (adjusted OR=2.5; 95% CI: 2.2 to 2.9) to have an emergency department transfer over a 6 month follow-up compared to those who had been in long-term care 90 days or longer.	data (not a subset), so generalizable to Ontario, but possibly not other provinces or other time periods (data were from 2005). Some potential confounders adjusted for in the analysis, but not all potential confounders would have been controlled for. The underlying reason for the increase in ED transfer could not be ascertained from the study data. Factors that could have potentially impacted the decision to transfer to the ED could not be determined (such family preferences)	LTC residents.
Fraher and Coffey, 2011¹¹ Multiple LTC facilities in the United Kingdom	Key Findings: Admission to LTC was distressing to some, but positive for others.	Selection of participants was by the director of the institution, with justification of the approach. Data were analyzed using	How well a client settles into LTC depends on their mode of entry and whether the facility suits their needs. Respect of the individual's needs and preferences can help minimize negative

Author, Year of Publication, Setting	Key Findings	Key Critical Appraisal Points	Authors' Conclusions
	Being admitted to a LTC facility that was considered unsuitable by the client was a cause of initial distress. Residents experienced feelings of sadness, but reported that they felt less socially isolated than prior to admission. It was reported that social isolation was greater in hospital than in the LTC residence. Lack of privacy was upsetting and residents were concerned about dignity and privacy.	a phenomenological approach, consistent with the objectives Unclear how the sample size was determined (i.e., did not state if saturation was reached) Data collection and analysis methods appeared to be rigorous Ethical standards appeared to be maintained. The relationship between the researcher and participants was not adequately considered or described. Key findings were clearly stated.	effects.
Sitter et al, 2011¹² Two personal care homes in Winnipeg, Manitoba.	Decrease in average MMSE from baseline to follow-up (28.0 ± 2.1 vs 24.6 ± 5.7; $p < 0.05$). Changes in the Geriatric Depression Scale, Braden, Katz ADL were not statistically significant	Questionnaires and other measures used were standard, well-validated tools used in geriatric assessment Visual estimation of food intake by trained researcher.	Changes to eating habits related to relocation stress may lead to further negative health outcomes.

Author, Year of Publication, Setting	Key Findings	Key Critical Appraisal Points	Authors' Conclusions
	Average weight decreases from baseline to follow-up, but the change was not statistically significant (80.2 ± 23.3 kg vs 77.0 ± 20.1 kg, $p > 0.05$) Increase in medication use over baseline reported for some drug categories (analgesics, supplements, bowel medications) and increase in average number of medications (data not shown) Reduced serum iron levels and mean corpuscular hemoglobin concentration from baseline ($p < 0.05$). Mean vitamin D levels increased from baseline (p-value not reported) 50% of participants consumed less than 50% of Canada's Food Guide recommended servings.	No control or comparison group No control or adjustment for potential confounding variables in the analysis. Lack of statistical power to detect change over time related to the sample size of 13 or fewer for comparisons. Less than one-half of eligible clients agreed to participate. Further the sample size was small. This could limit the generalizability of the findings. Generalizability to other locations is unclear. Only 9 of the 13 participants had data at both time points for baseline and follow-up comparison. Some statistical techniques were not appropriate for a small sample size. No data provided on the categories of medications	

Author, Year of Publication, Setting	Key Findings	Key Critical Appraisal Points	Authors' Conclusions
		that were reported to increase in use.	
Barredo et al, 2008 ¹⁴ Single LTC residence in the United States	Relevant themes Reaction to placement ranged from positive to negative. Positive: gains in social interaction Negative: loss of independence, relationships and activity	Specific qualitative design paradigm not described, so cannot tell if it was consistent with the research objective. Selection of participants was with the assistance of staff, but did not appear to be purposive Unclear how the sample size was determined (i.e., did not state if saturation was reached). Data collection and analysis methods appeared to be rigorous. Ethical standards appeared to be maintained. The relationship between the researcher and participants was not adequately considered or described. Key findings were clearly stated.	Losses experienced by those transitioning to LTC are cumulative
Saunders et al, 2008 ¹³	Relevant themes:	Specific qualitative design	There is a need for a

Author, Year of Publication, Setting	Key Findings	Key Critical Appraisal Points	Authors' Conclusions
Single long-term care, aging in place complex in the United States	By third month following placement, residents reported loss of control of decision-making and having to rely on others to have needs met. - Described as embarrassing - Feelings of anger, frustration and helplessness Feelings of angst and sorrow were reported	paradigm not described, so cannot tell if it was consistent with the research objective. Method of selection of participants was not stated. Unclear how the sample size was determined (i.e., did not state if saturation was reached) Data collection and analysis methods appeared to be rigorous Ethical standards appeared to be maintained. The relationship between the researcher and participants was not adequately considered or described. Key findings were clearly stated.	relational model of care in assisted living facilities.

ADL Activities of Daily Living; ALC Alternate Level of Care; ED Emergency Department; HRQL Health-Related Quality of Life; LTC Long-term Care; MMSE Mini Mental State Examination; NH Nursing Home; OR Odds Ratio; RCT Randomized Controlled Trial; SD Standard Deviation

Question 3

What is the incremental effect of moving a client from one location (residence) to another location (residence) more than once in a short period of time (< 3 months or <6 months)?

Secondary sources

First Available Appropriate Living Option-type policies may potentially result in multiple transfers or relocations in a relatively short period of time, for example, from hospital to a LTC facility that is not a preferred option of the client (e.g., the first bed available within 100 km) and then a second relocation to a preferred facility when a bed becomes available). A report of Ontario's Ministry of Health and Long-term Care found that about 36% of clients are placed in their home of first choice and that many clients may accept the first bed offered to them while remaining on the waitlist for their preferred location.³⁰ Forty percent of clients on Ontario's LTC waitlist were already residing in LTC and remain on the list awaiting a bed in a different facility.³⁰ Proximity to family and caregivers has been identified as being of key importance when transitioning to LTC⁹ and placement in a non-preferred LTC facility has been described as distressing.⁹ It has been suggested that an increasing proportion of LTC residents have characteristics that would place them at risk of negative health outcomes if moved between facilities, such as high levels of dependency and dementia.¹⁶ Further, transitional care may be fragmented and routine transfers can be viewed as hazardous due to medical errors in communication, order transcription and pharmacy-related issues.¹⁶

Research reports

No studies were identified from the database searches or the grey literature that directly explored the incremental effects of multiple transfers on client health. One systematic review of the literature was identified that focused on the impact of forced relocation between nursing homes. This review did not directly address Question 3 or meet the inclusion criteria, but contained potentially informative findings.¹⁶ The objectives of the review were to identify and evaluate the evidence pertaining to the consequences and impact of relocation on LTC residents and to identify recommendations for the management and process of forced relocation, related to nursing home closure. Multiple databases were searched for the period between 2000 and 2012. The search was restricted to English language publications. Two reviewers screened titles and abstracts for potentially relevant publications and selected studies for inclusion. There was no restriction on study design. Meta-analysis was not performed due to heterogeneity in study design.

Ten articles were included in Holder and Jolley's review.¹⁶ Six studies reported on mortality, four on changes in physical health and eight on psychological health. Reported increases in mortality rates following forced relocation ranged from 8.7 to 45.8% in four included studies.¹⁶ One study found no

change in the mortality rate, while one other study found that mortality rates decreased following relocation, relative to the three years prior to relocation.¹⁶ Physical health outcomes included increased falls (one study); increased rates of depression and pressure sores (one study); decline in cognition, engagement, mood and ability to perform ADLs (one study); and increases in antipsychotic use (one study).¹⁶ One study evaluated a mass move between an older facility and a more specialized, newer facility, and found no evidence of relocation stress syndrome.¹⁶ The authors felt that this may be attributed to giving the residents ample notice of the move, having a social worker available, careful planning and moving to a 'better environment with more care'.¹⁶ One study explored the vulnerability of clients with cognitive impairment to relocation effects and found no evidence of greater vulnerability of those with cognitive impairment relative to those without.¹⁶ The authors of the review concluded that ill-planned relocation is stressful and linked to adverse outcomes, but carefully planned relocation moderates the likelihood of adverse outcomes.¹⁶ Limitations to this systematic review include lack of explicitly stated selection criteria for inclusion, no description of the data extraction and validation, and no quality assessment of the included studies. Further, the findings of the review may not be directly generalizable to Question 3 of this literature review.

Summary

No studies were identified from the database searches or the grey literature that directly explored the incremental effects of multiple transfers on the health of clients. One systematic review of forced relocation between nursing homes found that the experience was stressful and had an adverse effect on some health outcomes. However, the impact on mortality was variable. Carefully planned relocation may reduce the risk of adverse outcomes.

Question 4

What are the studies of ethical issues that come into play when developing a LTC wait list management policy (e.g. justice, choice, resource allocation)?

Secondary sources

Long-term care beds can be considered a scarce healthcare resource. LTC waitlist management policies attempt to address the shortage of long-term care beds that many provinces face through more efficient allocation. In healthcare resource allocation, there are several key ethical considerations. Justice or fairness, autonomy or choice, and equitable resource allocation are examples of ethical considerations when developing policies that allocate LTC beds.³¹ Justice refers to ensuring, where possible, that people have equal access to basic health care resources.³¹ Autonomy is the right of people to control their healthcare and treatment, where feasible.³¹ Equity is concerned with the distribution of benefits and costs to distinct individuals or groups.³¹

One opinion piece identified from the grey literature search discussed the debates around efficiency and equity in the allocation of LTC beds.¹⁸ The author suggests that many individuals waiting in hospital for LTC placement are not easily placed and have characteristics associated with lower socioeconomic status (such as obesity and psychiatric disorders), which raises questions of equitable access for these groups.¹⁸ The author further argues that a focus is needed on how new and existing facilities can accommodate these clients with specialized needs to ensure equitable access.

A second opinion piece identified from hand-searching discussed the impact of waiting for LTC placement in acute care beds on emergency department overcrowding from an ethical perspective.³ The authors identify distributive justice as a key ethical principle to consider in overcrowding of emergency departments. According to this principle, under scarcity of healthcare resources, treatment priority should be given to those patients who are in the greatest need. The authors argue that many individuals who present to the emergency department require high levels of care in the initial 24 hours of presentation, including specialized inpatient services (e.g., advanced diagnostic tests, surgery, or intensive acute care). They further state that those near the end of hospitalization have the lowest need for hospital care, particularly those awaiting LTC placement. From the perspective of distributive justice, priority for beds would be given to those requiring transfer from the emergency department. The authors highlight the need for policymakers, politicians, and others in society to address this issue, particularly as the population ages and the potential for delayed discharge to LTC increases.

Research reports

One qualitative description of the LTC placement process under the FAALO policy in Alberta was identified from the database searches.³² This study is not directly relevant to Question 4 as it did not evaluate ethical issues in long-term waitlist management. However, the authors did identify difficulties with the placement of individuals with mental illness (at the initial match to a FAALO bed and then subsequent match to a bed at one of their preferred locations). The authors attributed this, in part, to the use of centralized software that performs matching based upon standard categories which might not adequately reflect the patient. The authors further state that the FAALO policy restricts the degree of choice (autonomy) that patients have so that they can be moved out of hospital more quickly.

Summary

Justice or fairness, autonomy or choice, and equitable resource allocation were identified as ethical considerations when developing policies that allocate LTC beds when healthcare resources are scarce.

Question 5

Is there evidence of the effectiveness of FAALO or similar policies on patient flow in acute or long-term care?

Secondary sources

Occupancy of hospital beds by alternate level of care patients and delay in hospital discharge has a negative impact on patient flow throughout hospitals. Occupancy rates have been used as a measure of quality, since high occupancy is associated with a number of problems. Emergency department crowding,^{1,33} cancellation of day procedures,¹ and poor coordination of sub-acute care may occur when discharge from hospital is delayed and the occupancy rate increases.^{1,22,34} A lack of a needed hospital bed can delay transfer to medical and surgical wards and ICU.³³ The placement of operating rooms 'on hold' can occur when there is a lack of available beds to accommodate patient transfer and can lead to decreased efficiency, increased costs and decreased patient satisfaction.³⁵ Emergency department overcrowding has a negative effect on quality of care, as evidenced by increased risks of errors, excess morbidity and mortality.³³ A literature review of factors that contribute to the ICU discharge process found discharge delays from ICU were attributed, in part, to resource constraints on the wards.³⁶ Approximately 81% of delayed discharges from ICU were because there was no available bed in the hospital, with the delay for ICU discharge being about 21 hours.³⁶ Further, a lack of ward beds resulted in 16% of planned discharges from the ICU being unsuccessful.³⁶ While these potential issues related to delayed discharge and high occupancy rates have been identified in the literature, the cited studies are not specific to clients waiting for LTC placement, nor do they evaluate the impact of first available bed policies on these areas of flow in the hospital.

Research reports

Two relevant reports (one literature review from the database search¹⁷ and one primary research study from the grey literature search⁴) that evaluated the impact of waitlist management policies were identified. The literature review assessed the impact of health policies intended to reduce delayed discharges.¹⁷ The authors stated that they searched all key medical databases to identify relevant literature, but details of the methodology for the literature review were not provided. There was no description of items such as the databases searched, search time frame, search strategy, methods related to literature selection such as criteria and process, and data extraction methods. Specific research questions or objectives were not stated. Delayed discharge was defined as the "situation where a patient is deemed to be medically well enough for discharge but where they are unable to leave hospital because arrangements for continuing care have not been finalized."¹⁷

One study included in the literature review evaluated the policy impact of the Community Care Act in the United Kingdom which allowed the National Health Service to charge Social Services Departments a daily fee if they failed to provide required post-discharge services within 48 hours of a patient being ready for discharge. A reduction in delayed transfers and shortened average hospital stays were found following the implementation of the Act; however, there was also an increase in readmission rates from 5.4% in the year prior to 6.7% in the year following implementation of the Act. In another report included in the literature review, concerns about people feeling pressured to make decisions about LTC placement from their hospital beds were raised. This report also cited that inappropriate discharge to residential care was also a policy consequence given that a large proportion of older people moved directly from hospital to LTC. The authors of the literature view concluded that policies generally had a positive impact on delayed discharges, but there were concerns about readmission and lack of consultation with patients with respect to LTC placement. The major limitation of this literature review was the lack of description of methodology, making it difficult to assess its rigor and interpret the findings in that context.

One identified primary research study assessed the impact of the Community Care Act on delayed discharges in the NHS.⁴ This study was not included in the previously described literature review.¹⁷ The study's objective was to assess whether changes in efficiency have been realized as a result of the Act. Trends in delayed discharge, hospital activity, length of stay and numbers of emergency readmissions were reviewed using a number of data sources. Details of the specific databases, number and proportion of patients captured in the databases, definitions of key variables and outcomes and methods of statistical analysis were not reported. The authors found that the steep reduction in the number of patients with a delayed transfer pre-dated implementation of the Community Care Act and as such, could not attribute the decline solely to its implementation. Emergency readmission rates within 28 days of discharge increased in younger adults (aged 16–74 years) and in older adults (aged 75 years and older). The authors concluded that the fall in delayed discharge preceded the Act and that the increase in readmission rates was of particular concern. The main limitation of this report was the lack of description of its methodology, making it difficult to interpret the findings without this context.

Summary

The Community Care Act was implemented in the United Kingdom to help address issues related to delayed discharges from the acute care setting to LTC. One research study and one literature review identified a reduction in delayed transfers and shortened average hospital stays following the implementation of the Act; however, there was also an increase in readmission rates over the same time

period, which was concerning. Further, the reduction in delayed discharge may have pre-dated implementation of the Act.

Question 6

Have there been legal challenges to FAALO policies in Canada?

Findings

Legal discussions of first available bed policies in Canada were identified from the grey literature searches. One prominent case from British Columbia was the focus of questioning in the British Columbia Legislature and prompted investigation by the Deputy Minister of Health.³⁷ Under a first available bed policy, a 91 woman was transferred from a hospital to a nursing home, 100 km away from her 96-year old spouse. She died within 48 hours of the transfer and her spouse died less than two weeks later. The grey literature review to not identify any legal action subsequent to these events that occurred in 2006.

In the report to the Minister of Health, the following points were made:

"Mrs. Albo was very close to the end of her life at the time of her transfer to Grand Forks. It is difficult to know exactly what impact the transfer played in her death. In the following ways, quality care was not delivered:

Mrs. Albo's discharge from hospital to a residential care facility in Grand Forks did not constitute quality care for the following reasons:

- Her heart condition was end-stage and she was medically fragile;
- She was a more appropriate candidate for palliative care rather than residential care; and
- Transferring her to a facility so distant from her home was imprudent given her advanced age, the fact that her frail and very elderly husband had been her long-term primary care-giver, and there had been no time to prepare either of them for their separation.

The lack of attempts by providers and senior staff involved in her case to take responsibility for a "pause and think" decision, which might have resulted in different and more creative options, did not constitute quality care.

The lack of integration of key information from concerned family members into the options offered to her and her family did not constitute quality care."^{38(p 12)}

One of the key recommendations of the report was to review the application of the first available bed policy to better clarify criteria for decision-making in regard to:

- "the feasibility of a family's ability to remain connected in the case of patients being placed outside their home community

- any special considerations which should be taken into account in regard to ongoing medical care;
- identification of the key decision-makers and an appeal process for families who disagree with the decision."³⁸(p 13)

In Ontario, the LTC placement process permits clients to choose up to five homes in their order of preference.³⁰ Clients are placed on waitlists for those homes according to their level of priority and date of application to each home.³⁰ In Ontario, the application for LTC placement is managed through Community Care Access Centres (CCACs), who have employees that work out of hospitals and are in charge of placements for that hospital.³⁰ The Ontario Ministry of Health and Long-term Care reiterated in a recent report that under the Long-term Care Homes Act of 2007, clients have the right to choose the LTC homes to which they wish to apply and clarified that Local Health Integration Networks (LHINs) cannot require clients to make their selections from a predetermined list of alternatives.³⁰ The Ministry states that "clients can only be placed in homes that are acceptable to them."³⁰ However, they noted deviations from this interpretation in that two CCACs required clients who were designated as 'crisis clients' to select from a list of homes with vacancies or short waitlists, if their preferred homes were not available. Further, another CCAC had a policy in place up to 2011 that required clients to select all homes within a 70 km radius of their residence. The Ministry required this CCAC to change its policy.

There have been reports to the Advocacy Centre for the Elderly of instances where elderly clients and their families and caregivers have been misled about the placement process for LTC, suggesting that they must apply for five homes when only one is needed, that they have to accept homes from a short list supplied to them and that they have to take the first available bed. As well, once clients are considered delayed discharge or alternate level of care, some hospitals have attempted to make patients pay a per diem rate (up to \$600 in some instances) while waiting in hospital for LTC. Compliance with the Long-term Care Homes Act of 2007 only permits a per diem rate of \$56.14, which is aligned with the per diem rate for a long-term care bed. According to a briefing paper by the Advocacy Centre for the Elderly³⁹ provisions of the Long-term Care Homes Act and the Health Care Consent Act hold that the decision to be placed in LTC and the location is up to the applicant and that these acts do not, in any way, give this role to hospital staff. They state that "For this reason, a person cannot be "offered" a bed to which they have not applied, and not taking such a bed can therefore not be deemed a refusal. Beds can only be offered after the applicant/SDM (substitute decision maker) consents to their application being sent to the home, the home accepts the application, and the CCAC offers the bed in accordance with the regulations."³⁹(p 6) In the legal opinion of the Advocacy Centre for the Elderly, while LHINs can designate hospitals as being in "crisis" when the hospital experiences capacity pressure, they are still prohibited from requiring that ALC patients take any LTC bed that becomes available.³⁹

One legal challenge to paying per diem rates while waiting for LTC placement was identified. In *Duffy vs. OHIP* (Ontario Health Insurance Plan), a client who was waiting for LTC placement in hospital was charged \$120 per day for a bed after refusing to list more than three homes on her LTC application. The Health Services Appeal Board found that the amount being charged was completely arbitrary and ruled that the fees be covered by OHIP.³⁹

Summary

A report to the British Columbia Ministry of Health recommended that the application of the first available bed policy be reviewed to clarify criteria for decision-making under this policy to ensure that it is consistent with what would be considered quality care. In Ontario, the Ministry of Health has clarified that charging of fees in excess of the per diem rate for basic accommodation in LTC while waiting for LTC placement in hospital is not permitted. Charging of such fees has also been challenged legally and it was found that this was not permissible.

Limitations

There are limitations to this literature review that should be considered when interpreting the findings.

Literature search

While the database searches were developed to be comprehensive and the search strategies were reviewed for completeness by other team members, it is possible that relevant literature may have been omitted. Review of the included studies by a content expert did locate one additional relevant study not captured in the database searches. Further, the search was limited to the recent literature (January 2008 to August 2013) and to English language publications. Literature prior to 2008 was not included in the review, but could potentially include evidence that was relevant to the research questions. The Grey Literature was searched using a standardized checklist of key internet sites, but again, it is possible that not all relevant literature was captured. Given these limitations, the contents of this literature review should not be viewed as a true systematic review of all available evidence related to the six research questions.

Study selection, data extraction and quality assessment

While studies were selected according to criteria that were defined by the population, intervention, comparator, and outcomes of interest (PICO dimensions) and relevant study designs, the screening and selection was performed by a single reviewer. Data extraction and quality assessment were also performed and verified for accuracy by a single reviewer. This approach to study selection, data extraction and quality assessment is consistent with rapid literature reviews, but systematic literatures generally use more rigorous methodological standards. Generally, in a systematic review, two reviewers

would screen abstracts, select papers for full-text view and arrive at consensus for inclusion. Further, data extraction in a systematic review is more rigorous in that either two reviews extract data and compare results or one reviewer extracts data and the other verifies the data for accuracy. Quality assessment is somewhat subjective, so it would have been preferable to have two reviewers perform the quality assessment, compare results and reach consensus.

Data synthesis

The quantitative data were not appropriate for meta-analysis given the heterogeneity in study design and outcomes assessed. Further, data presented in several of the included studies was insufficient for meta-analysis. As such data were summarized narratively.

Limitations to the body of evidence

The evidence for each research question was limited in volume and methodological strength. Generally, the quantitative study designs used would be considered weak, particularly the cross-sectional designs and single group follow-up studies. Cross-sectional designs limit the ability to determine timing of events and make causal inferences. Further, without a control group, it is not possible to determine the effects of confounding factors, natural progression or change over time, or control for co-intervention effects. The strongest study design was a cohort study that appeared to be well designed overall.¹⁰ Sample sizes of some studies were small, which could impact the generalizability of the findings and power of the statistical analyses. Generalizability may be further limited to other jurisdictions or time periods and by differences in standards of care, healthcare policies, and underlying differences in the patient populations.

Discussion

The transition to LTC is a major life event. The decision to be placed in LTC is often carefully considered over a period of time; however, this decision may also be precipitated suddenly by major health events that preclude return to independence and necessitate immediate placement once the client is no longer in need of acute care. For some, who have already made the decision to apply for long-term care, a major health event or sudden change in health status may make the need for placement more urgent, sooner than previously planned for. The shortage of available LTC beds, particularly those at a preferred location or in facilities that can accommodate more specialized needs, can delay discharge from acute care settings to an appropriate LTC bed. Waitlist management policies, such as FAALO, attempt to alleviate the strain on acute care beds by transitioning clients from hospital to an available LTC bed. This bed may not be considered appropriate or preferred by the client, but provides a temporary placement for clients ready for discharge from acute care until a bed becomes available at their preferred location.

There are potential benefits and unintended consequences of FAALO and similar waitlist policies. Concerns related to waiting in hospital for LTC placement can be considered from economic, clinical and humanistic perspectives. From the economic perspective, hospital care is costly and hospital beds are in short supply. High occupancy rates have been associated with inefficiency in flow between departments (e.g. from emergency departments to wards or from ICU to ward beds).^{1,33} Further, high occupancy rates may contribute to nosocomial infection rates.¹⁹⁻²² Delayed discharge to LTC is one factor which can contribute to occupancy rates that are higher than desired.²² Other clinical considerations related to waiting in hospital for LTC placement include functional and cognitive decline, deconditioning and loss of independence with extended hospitalization.^{1,18,23} Acute care settings may lack the appropriate targeted rehabilitation programs or other programs that promote and maintain independence in older adults.²³ Mental health may be adversely affected by waiting in hospital for LTC placement. Social isolation, loss of motivation, depression and anxiety may occur.^{1,18} The studies included in this literature review provided some evidence to support these concerns. The mental health burden associated with waiting for LTC placement was evidenced qualitatively through themes of anxiety⁶ and quantitatively through higher rates of anxiolytic and psychotropic drug use.¹ Further, psychiatric symptoms (crying, sadness) were also directly observed.⁷

The potential benefit of FAALO and other waitlist management policies relate to gains in efficiency and improved flow in the healthcare system, which could reduce emergency department crowding and ensure that hospital beds are available for transfer between wards when needed. There was some evidence of delayed transfers and shortened average hospital stays following the implementation of legislation aimed at reducing the frequency of patients experiencing a delay in discharge.⁴ However, there was also an increase in readmission rates over the same time period, which may have been an unintended consequence of the policy.⁴

The impact of initial LTC placement was mainly studied using qualitative approaches that focused on the experience of the patient with the adaptation process. The stress associated with transitioning to LTC has been documented in previous literature. Qualitative studies included in this literature review identified feelings of loss related to different aspects of life during the transition to LTC, as well as feelings of sadness and distress.^{11,13-15} Proximity to family has been noted as a key characteristic in selecting an appropriate nursing home.^{6,9} Having to accept placement at a location that was considered unacceptable by the client was identified as one source of distress.¹¹ Thus, policies that require clients to accept the first available bed, regardless of proximity to family, could potentially be distressing to clients. Clients tended to focus on their negative experiences with initial LTC placement, but gains in social interaction were also noted. Quantitatively, an increased risk of emergency department transfer was found for clients recently placed in LTC¹⁰ and nutritional status appeared to be adversely affected in

a small study, which the authors attributed to the stress of transfer.¹² The literature review did not identify any evidence related to the incremental effect of multiple relocations in a short period of time, which could potentially happen under a policy such as FAALO. One review of the impact of forced relocation to a different LTC facility suggested that the negative impact could be moderated through careful planning and organization of the move.¹⁶ While the initial placement under first available bed policies could potentially be considered "forced," the relocation once already placed in a LTC bed is not technically "forced". Thus, the findings of this review do not directly relate to multiple placements in a short period of time, but may suggest if relocation to the preferred home is carefully planned, it is possible that the effects on client health may be reduced.

The impact of waitlist management policies on patient autonomy is one ethical consideration in their development and implementation.^{3,31} First available bed policies and other waitlist management strategies that restrict the client's freedom of choice potentially violate this ethical principle. In Ontario, legislation prevents hospitals and others involved in the LTC placement process from impinging upon autonomy by allowing only the client or substitute decision-maker to select the LTC homes (up to five) which they feel are appropriate.³⁰ Despite this, there have been instances where hospitals have attempted to implement policies that do not align with the legislation.³⁰ When this has happened, it appears that the Ontario Ministry of Health supported and enforced the client's freedom to choose. Concerns related to equity in the LTC placement process have also been expressed, related to the observation that a significant proportion of those waiting have psychiatric issues. The need for improving capacity to meet the needs of these clients has been raised.^{18,32}

While first available bed policies exist in several provinces, only one legal challenge in Ontario was identified and was related to charging a per diem rate for waiting in hospital after refusing a LTC bed that was not considered appropriate by the client.³⁹ It was determined that this practice contravened the relevant legislation. Legal opinion pieces have noted that the decision to implement such charges has been inconsistent and arbitrary across institutions and even within the same institution in terms of the timing of initiation of such fees and the amount.^{37,39} No legal challenges to first available bed policies in other provinces were identified.

Conclusions

The recent evidence relating to the consequences of waiting for LTC placement, the initial impact of placement and the effect of LTC waitlist policies on patient flow in other areas of the healthcare system was limited in quantity and in methodological rigor. These points should be considered in the interpretation of the findings of this review. The identified evidence suggests that the uncertainty of waiting for placement was a source of anxiety for patients and that the initial placement was associated

with feelings of loss. The importance of choice was noted by clients and is an ethical consideration in developing waitlist management policies. Decreased length of stay, but increased readmission rates were observed following the implementation of legislation intended to reduce delayed discharges from hospital. No literature was identified that directly evaluated the impact of multiple moves on the health of LTC clients, so no conclusions can be made with respect to this research question.

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Appendix 1 – Database search terms

Question	Search Terms
1) What is the impact on the health of clients waiting in acute care and in the community for LTC placement?	Long-term care concept ▪ Long-Term Care ▪ Nursing Homes ▪ Housing for the Elderly ▪ Continuing care ▪ Extended care or assisted living ▪ Aged care ▪ Care home ▪ Nursing facilities ▪ Residential facilities ▪ Supportive living Waitlist concept ▪ Waiting ▪ Waitlist ▪ Bed block/bed blocking ▪ Alternate level of care ▪ Delayed discharge ▪ Bed occupancy ▪ Long-term care placement ▪ Transition to long-term care Outcomes/health impact concept ▪ Disease Management ▪ Accidental Falls/falls ▪ Infection ▪ Deconditioning ▪ Functional decline ▪ Activities of Daily Living ▪ Executive Function ▪ Functional status ▪ Function ▪ Cognition ▪ Cognitive disorders ▪ Dementia ▪ Mental health ▪ Health status ▪ Health outcome ▪ Quality of life
2) What is the impact on the health of a client when the client first moves from community or acute care to long-term care?	Long-term care concept ▪ Long-Term Care ▪ Nursing Homes ▪ Housing for the Elderly ▪ Continuing care ▪ Extended care or assisted living

	▪ Aged care ▪ Care home ▪ Nursing facilities ▪ Residential facilities ▪ Supportive living Transition concept: ▪ Transition to adult care ▪ Transition ▪ Institutionalization ▪ Patient transfer ▪ Transfer ▪ Placement ▪ Health transition ▪ Life change events Health impact concept ▪ Functional status ▪ Function ▪ Cognition ▪ Cognitive disorders ▪ Dementia ▪ Mental health ▪ Health ▪ Health status ▪ Health outcome ▪ Quality of life ▪ Social adjustment ▪ Adaptation, psychological ▪ Adaptation, physiological
3) What is the incremental effect of moving a client from one location (residence) to another location (residence) more than once in a short period of time (< 3 months or <6 months)?	Long-term care concept ▪ Long-Term Care ▪ Nursing Homes ▪ Housing for the Elderly ▪ Continuing care ▪ Extended care or assisted living ▪ Aged care ▪ Care home ▪ Nursing facilities ▪ Residential facilities ▪ Supportive living Relocation Concept ▪ Patient transfer or transfer ▪ Relocation ▪ Readmission
4) What are the studies of ethical issues that come into play when developing a LTC wait list management policy (e.g. justice, choice,	Long-term care concept ▪ Long-Term Care ▪ Nursing Homes

resource allocation)?	▪ Housing for the Elderly ▪ Continuing care ▪ Extended care or assisted living ▪ Aged care ▪ Care home ▪ Nursing facilities ▪ Residential facilities ▪ Supportive living Waitlist concept ▪ Waiting ▪ Waitlist ▪ Bed block/bed blocking ▪ Alternate level of care ▪ Delayed discharge ▪ Bed occupancy ▪ Long-term care placement ▪ Transition to long-term care Ethics or ethical
5) Is there evidence of the effectiveness of FAALO or similar policies on patient flow in acute or long-term care?	Long-term care concept ▪ Long-Term Care ▪ Nursing Homes ▪ Housing for the Elderly ▪ Continuing care ▪ Extended care or assisted living ▪ Aged care ▪ Care home ▪ Nursing facilities ▪ Residential facilities ▪ Supportive living ▪ Alternate level of care Waitlist concept ▪ Waiting ▪ Waitlist ▪ Bed block/bed blocking ▪ Alternate level of care ▪ Delayed discharge ▪ Bed occupancy ▪ Long-term care placement ▪ Transition to long-term care

	Patient Flow Concept ▪ Patient flow ▪ Resource utilization ▪ Process of care ▪ Healthcare delivery
6) Have there been legal challenges to FAALO policies in Canada?	Long-term care concept ▪ Long-Term Care ▪ Nursing Homes ▪ Housing for the Elderly ▪ Continuing care ▪ Extended care or assisted living ▪ Aged care ▪ Care home ▪ Nursing facilities ▪ Residential facilities ▪ Supportive living ▪ Alternate level of care Waitlist concept ▪ Waiting ▪ Waitlist ▪ Bed block/bed blocking ▪ Alternate level of care ▪ Delayed discharge ▪ Bed occupancy ▪ Long-term care placement ▪ Transition to long-term care Legal or legal challenge

Appendix 2 – Selection criteria

Question	Selection Criteria
1) What is the impact on the health of clients waiting in acute care and in the community for LTC placement?	▪ Population: Adults in hospital or community ▪ Intervention: Waiting for placement in long-term care ▪ Comparators: No comparator or immediate placement ▪ Outcomes: ○ Disease Management ○ Accidental Falls/falls ○ Infection ○ Deconditioning ○ Functional decline ○ Activities of Daily Living ○ Executive Function ○ Functional status ○ Function ○ Cognition ○ Cognitive disorders ○ Dementia ○ Mental health ○ Health status ○ Health outcome ○ Quality of life ▪ Study Design ○ Inclusion: Systematic reviews, full reports of quantitative or qualitative primary research studies of any design ○ Supplementary information: editorials and review articles
2) What is the impact on the health of a client when the client first moves from community or acute care to long-term care?	▪ Population: Adults in hospital or community ▪ Intervention: Initial placement in long-term care ▪ Comparators: No comparator or remaining in community or remaining in hospital ▪ Outcomes: ○ Functional status ○ Function ○ Cognition ○ Cognitive disorders ○ Dementia ○ Mental health ○ Health ○ Health status ○ Health outcome ○ Quality of life ○ Social adjustment ○ Adaptation, psychological ○ Adaptation, physiological ○ Medical errors ○ Accidental Falls/falls ▪ Study Design ○ Inclusion: Systematic reviews, full reports of quantitative or qualitative primary research studies of any design ○ Supplementary information: editorials and review articles

3) What is the incremental effect of moving a client from one location (residence) to another location (residence) more than once in a short period of time (< 3 months or <6 months)?	▪ Population: Adults in hospital or community ▪ Intervention: Relocation ▪ Comparators: No comparator or remaining in current location ▪ Outcomes: ○ Functional status ○ Function ○ Cognition ○ Cognitive disorders ○ Dementia ○ Mental health ○ Health ○ Health status ○ Health outcome ○ Quality of life ○ Social adjustment ○ Adaptation, psychological ○ Adaptation, physiological ○ Medical Errors ○ Accidental Falls/falls ▪ Study Design ○ Inclusion: Full reports of quantitative or qualitative primary research studies of any design
4) What are the studies of ethical issues that come into play when developing a LTC wait list management policy (e.g. justice, choice, resource allocation)?	▪ Population: Adults in hospital or community ▪ Intervention: LTC waitlist ▪ Comparators: No comparator or any comparator ▪ Outcomes: Ethical issues ▪ Study Design ○ Inclusion: Systematic reviews, review articles, opinion pieces and primary research studies
5) Is there evidence of the effectiveness of FAALO or similar policies on patient flow in acute or long-term care?	▪ Population: Adults in hospital or long-term care ▪ Intervention: LTC waitlist policy ▪ Comparators: No comparator or any comparator ▪ Outcomes: ○ Process measures ▪ Wait times ▪ Cancelled or rescheduled procedures ▪ Transfer times ▪ Other measures of flow ○ Resource utilization ▪ Study Design ○ Inclusion: Systematic reviews, full reports of quantitative or qualitative primary research studies of any design ○ Supplementary information: editorials and review articles
6) Have there been legal challenges to FAALO policies in Canada?	▪ Population: Adults in hospital or long-term care ▪ Intervention: FAALO waitlist policy ▪ Comparators: Not applicable ▪ Outcomes: Not applicable ▪ Study Design: Not applicable

Appendix V: Resident and family interview report

Resident and Family Interviews

February 2014

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We would like to extend a sincere thank you to the residents and their family members who generously and openly shared their experiences with the continuing care placement process with us. Thank you also to those continuing care facility operators and staff who did the hard work of connecting us with these residents and their family members. If it weren't for all of you there would nothing to report on here.

Introduction

This small qualitative research project is one stream of inquiry in this review of the AHS continuing care waitlist policy which specifies how Alberta citizens are placed in the first available appropriate living option (FAALO). This policy is often referred to as the FAALO policy. This purpose of this project was to capture the views and experiences of clients and families in Alberta who have recently gone through the placement process and have some experience with the FAALO policy.

Methods

Sampling strategy: Who we talked to

Interview participants (residents and their family members) were recruited through six Alberta facilities located in five cities or as, three in the northern part of the province and two in the south. A purposive sampling strategy was used, that is we purposively sought out people who were interested in talking about their experience with continuing care placement, with a goal of maximum variation. We sought to interview people who would bring a broad range of perspectives. About half of the interview participants were recruited through two large facilities in Calgary that experience a lot of turnover because of the FAALO policy. We were able to recruit a variety of participants, with respect to cultural background and other key contextual factors (e.g., work experience; education; and economic wellbeing).

Given the purpose of the review, we wanted to speak primarily to people who had the experience of not moving directly to a preferred option. We did, however, also want to speak to some people who had the experience of being placed in their preferred option – for comparison purposes. All of the interview participants recruited who were placed in a FAALO (or had their family member placed in a FAALO) were still in this facility at the time of the interview. All of the participants recruited were involved family members themselves, or were residents who have involved family members who saw them regularly.

Eighteen interviews were conducted in total, five with residents and thirteen with family members. Family members included spouses, daughters, sons and a nephew. One interview was conducted with two daughters of the same resident, who requested to be interviewed together. So we did speak with a total of 19 individuals. Thirteen of the interviews conducted pertained to residents placed in a FAALO that was not a preferred option, and five pertained to residents who were placed in a preferred option. See **Table 1** for a summary of the interview participants. In addition, informal conversation with continuing care facility operators and nursing staff took place during the recruiting process. Some of what we heard from these conversations is referenced in footnotes when they supported the views expressed by residents and/or their families.

Table 1: Interview participants

	Calgary [2 facilities]		Medicine Hat		Redwater		Grande Prairie		Total
	Family	Resident	Family	Resident	Family	Resident	Family	Resident	
Placement in a non-preferred	8*	3	3	0	0	0	0	0	14
Placement in a preferred option	0	0	0	1	2	0	1	1	5
Total	8	3	3	1	2	0	1	1	19

**Two of these family members were interviewed together about their experience with the placement of their mother in a non-preferred continuing care setting*

Data collection and analysis: What we did

Two semi-structured interview guides were developed to guide the conversations with residents and family members, one for people placed in a FAALO that was not one of their preferred options, and one for people who were placed in one of their preferred options (see Appendix A). Three of the eighteen interviews, all with residents, were conducted in-person at a continuing care facility. The remaining fifteen interviews were conducted over the telephone at a time that worked for the interview participants.

The interviews ranged in length from 25 to 90 minutes, with the average being about 45 minutes. The interviews were audiotaped with the permission of the interview participants and transcribed verbatim. Detailed notes were also taken during the interview. Data was analyzed using commonly accepted qualitative data analysis methods, with the goal of identifying common themes that emerged through the interviews.

This project was carried out following commonly agreed to ethical conduct for research involving people. Only people who had some recall of the placement process, and who were able to provide informed consent, were eligible to participate in this interview project. Many of the residents placed in continuing care facilities have some degree of dementia, and so were unable to participate directly. That is why we spoke with many family members. All interview participants provided their verbal consent; that is, the consent form was reviewed and verbal consent audio-recorded. Participants were given a copy of the consent form for their records (see Appendix B).

Findings: What we learned

The findings from these interviews are reported by broad question area, with the themes that emerged under each of these interview topics described. As is common in qualitative research, a number of case examples and quotes are included here so as to provide important context. It is important to note that what is reported here are peoples' understandings and perspectives, as well as their descriptions of their experiences. The intent here is to as accurately as possible represent the voices of the interview participants.

1. Waiting for a bed in a continuing care facility

The circumstances that led to a move to a continuing care facility

Most of the interview participants were waiting, or had a family member waiting, for placement in a continuing care bed in an acute care hospital or a rehab setting. Many of these people arrived in hospital as a result of a fall, or repeated falls. Sometimes the fall resulted in a serious injury (e.g., hip fracture, back fracture) and sometimes it was just the number of falls that was concerning. Others ended up in hospital because their current living arrangement (either at an assisted living facility or living in a family home) could no longer provide the level of care required, or they became suddenly ill requiring a hospital admission.

In a number of cases a family member had been trying to do everything they could to keep their family member living at home with them, or providing extra supports so that they could remain in an assisted living facility, but had to make the decision to place them on a wait list for continuing care. A number of people were in the situation of caring for a family member who required 24-care. That is, they could not be left alone for any period of time because of dementia. In a few cases, an individual was placed on the waiting list while they were living in the community, but they ended up in hospital and were placed in a continuing care bed from there. There were also a number of examples where multiple moves took place over a short period of time, as it often seemed like once the individual began to deteriorate their care needs changed quickly necessitating moves from assisted living to supported living to long term care.

In one case a woman moved from her own condo to an assisted living facility within walking distance of her daughter's home. Within a few months, however, it became apparent that she could not manage on her own and was assessed as requiring an SL4D-secure placement. Their first choice was to move into this type of unit in the same facility, and this level of care was available. She was moved to a first available bed in another facility; five weeks later this family did get a call from the first choice facility saying a bed was available. By this time, however, the resident no longer needed a secure bed, as she had become confined to a wheelchair, and was re-assessed as requiring SL4-open. She was then put on a waitlist for this level of care. Just prior to being moved to another facility, however, she was re-assessed once again as requiring full care. She moved to another FAALO (i.e., still not in their first choice facility). This woman has moved three times in less than 18 months, and is now settling into the long term care facility. The family is happy with the care being provided here and has made the decision to take her off the wait list for her first choice.

"Up until November 6th, I was sort of the sole caregiver of him and he was progressively getting a little bit worse. And he started to fall. And he fell...maybe in three months he fell about four times...My children kept saying that prior to him falling that I should start looking for a place for him and also I was told by [the doctor] who diagnosed him with dementia...that he would be in a home two years ago. But I didn't have the heart to make that decision, so when he fell that decision was taken out of my hands." [Spouse]

"And well, the doctors thought that maybe it would be best if she be going into a long-term facility because of all her needs, right? And also, to give me a break, because I've been taking care of her for like several years...but like I said, I was happy. Actually I didn't think they were going to place her that fast. They made it a priority because they wanted her into the nursing home and they thought I was being stressed out. I was more being stressed out because I needed some help." [Daughter]

Only one of the interview participants had their family member admitted to a continuing care bed directly from the community, and in this instance it was a mother who was living with and being cared for by her daughter. At times it appeared as if the person was getting pressure from well meaning family members and/or healthcare professionals to put their loved one in a continuing care facility, when they were actually just asking for some help. This is what appeared to happen in this case.

In another example, a family member described the benefits of being proactive in considering a move to continuing care. In this case, the family was living in a small town that had a small long term care facility as part of their local hospital. When their elderly mother, currently living in a lodge, had to be admitted to hospital the physician recommended that she consider moving into a long term care bed as she was deteriorating and they had two beds available at that time. Looking back they are all very grateful that they made this decision, as their mother is getting great care and she is close by and can see her family daily.

How long people were waiting for a bed, and the impact the wait had on their health and wellbeing

The time people spent in hospital prior to being moved to a continuing care facility ranged in length from two weeks to a year, with the average being about a month. It was often difficult for residents and family members to determine which portion of that time was actually spent waiting for a placement. A number of people required active acute care for a period of time, before they were ready to be transferred. A number of people experienced very short wait times, once they had been assessed by transition/placement services and put on the waiting list. In general, wait times were reported as longer in big cities like Calgary.

Most people who were waiting in hospital themselves, or had a family member waiting in hospital, did not comment on the length of the wait being unexpected or difficult. One family member wondered why some people waited far longer than others in hospital before a continuing care bed became available. A few family members did describe their family member as deteriorating physically and/or cognitively while in hospital, some saying things like: *"She just wasn't the same after having the operation."* A younger woman with a degenerative neurological condition commented that she lost a lot of strength and walking ability while in hospital. *"I got in the wheelchair in the hospital and since then I've lost a lot of strength."* A number of people felt that they/their family member were not given enough physiotherapy and occupational therapy to maintain or rebuild their strength while in hospital, meaning that they moved to a continuing care facility in a weakened condition.

One family member described in some detail how she felt that the focus on efficiency in hospital care, in this case in a transition unit, contributed to the decline in his father's ability to walk and feed himself, as this quote illustrates.

"It was over a month anyway and in that time...I've had nothing but good things to say about the hospital staff in the transition unit. They were all very professional and they were very friendly and very efficient with their jobs. I guess efficiency is kind of the way I look at it. And why I say efficient is because they don't have a lot of time to let people sort of manage on their own. So what I saw was that my dad

deteriorated even further down the road, because he wasn't allowed to feed himself because he was too sloppy.... So it sort of went from walking and then I had just got him a walker probably about less than a month before he went into the hospital, because he was walking on his own and then he had a walker, and I brought his own walker from home to the hospital. But they didn't use it much...they used it when he did his little exercise, but like once or twice daily they would walk them around the unit floor. But other than that he was maintained in a chair. So he actually lost the ability to really walk on his own [and to feed himself] in the hospital." [Daughter]

One daughter commented on her Mom being charged \$40 a day while waiting in the hospital for a placement, explaining that her Mom was on a very limited income (i.e., CPP disability) since suffering a stroke eight years prior. She was also on dialysis. She wondered why this is necessary, as this quote illustrates: *"If the system is unable to accommodate her and she is unable to go home, why did they charge her after they assessed her as requiring continuing care. She had to wait three weeks in the hospital for a bed and pay this."*

Regarding the impact the wait had on family members, it was often the uncertainty about where their loved one would be moved to, how long it would take to get a placement, and how their family member would respond to the move that created the most difficulty. The wait in hospital for a bed to become available, knowing that it could be anywhere in the city/town, or even in another town, created worry for many people. A few people said that they just felt relieved that the first available bed was still in the city/town, rather than in a different town completely. So it was the anticipatory stress, and not knowing – the lack of information – that strongly affected many residents' and family members' experience with the placement process.

"Now that I have him in here I feel better too. I was always concerned where he was going to be and how the move was going to be...so he's just sitting there and you wait and wait and wait. Nobody is coming and saying anything to you....?" [Spouse]

With respect to wait times in the community, a number of people described waiting for some time in the community (i.e., 3-12 months), and a few people ended up in hospital before they were placed often because of falls or other medical events. In two cases where an individual had been awaiting placement for a number of months in the community, a move to a hospital was arranged because of concern about the caregivers' (spouses) health. In one case the move was arranged by a family physician, and in another case by an assisted living facility after consultation with the family. The understanding was that waiting in hospital would speed up the placement process.

These long waits in the community were hard on families who were wanting to keep their loved one home as long as they possibly could, but then when they just couldn't do it any longer and made the decision to have their family member assessed and put on a wait list for continuing care, the wait for a bed was just too long. We heard almost an identical story from two people, but in one case the husband ended up in the hospital because of a fall, and in the other because his wife became exhausted trying to care for him to the point that her own health was jeopardized. Both women described themselves at a breaking point. In this quote below, one of these women describes how she got to this point, after health professionals involved in her husband's care following a hip fracture and hip replacement advised her to have him placed out of hospital, but she felt she just wasn't ready.

"Because in my heart I just felt I had to [take him home]. I said I would know when to put him on the list. And I don't regret having him home. It was a long summer and it was good summer, but it wasn't easy...Our kids and grandchildren came from [USA] and we were able to be out at the acreage and we could spend family time together. The grandchildren can remember having one summer yet with grandpa"

you know. We were all together. Like I said, I was kind of stubborn, but in my heart I felt I had to do it and I told [family doctor] when I couldn't do it I would be reaching out for help. And it was in July when we finally started [the process of having him assessed and placed on the wait list]...I thought it wouldn't take that long and then finally by the end of October I was really worn right out." [Spouse]

In the one case where the individual was placed directly from the community, the daughter described the wait time as being quite short (i.e., about 6 weeks). This woman had heavy medical care requirements, which may have contributed to her being labeled as urgent. Indeed, in this case the family found that the placement happened too quickly, which may have contribute to the problems they experienced when she was moved into a facility.

In summary, the exact length of the wait for a continuing care placement was not the primary concern expressed by these residents and their families; rather it was the lack of ongoing communication before and during the wait time, and related to this, how well the actual wait time fit with peoples' needs and expectations.

2. Explanation and understanding of policies regarding placement in a continuing care facility

Who explained the policies, and what was their understanding of how they worked

All family members were able to identify that someone transition/placement services^{iv} spoke to them, either in person or on the phone, about the policies regarding waiting for and placement in a continuing care facility. Some of the residents we spoke to, however, could not recall anyone speaking with them about the policy or about selecting choices about where they wanted to move. A number of people said that their recollection was that someone told them where they were going. One individual stated: "I never even thought about it. I wasn't well enough to care."

Some people talked about their family member being moved into a hospital "transition unit", from an acute care ward, while awaiting placement. More in-depth information about placement options, and selecting choices, often didn't occur until the individual had been moved to this unit. Everyone was informed about the first available appropriate living option (FAALO) policy. That is, they understood that they had no choice but to take the first appropriate continuing care bed that become available within a defined geographic area, and

"And so she [a transition nurse at the hospital] came and talked to me and she told me about the first bed available policy. So that was the first thing we talked about. And in fact, she didn't even mention choices at that point...like he was in the hospital proper population for about a week or so and then was moved to the [hospital-based] transition unit. Once he moved into the transition unit, then I was told about the choices. Because while he was in the hospital itself, there was still some discussion on whether or not he would actually go back to his [assisted] living. And then the [assisted] living said no---and I concurred with this, because I could see that they just didn't have the capability of handling him at that stage. [Daughter]

^{iv} In some centres the term placement services was used and in others transition services. In very small towns, it was more likely that many of these conversations were held with hospital staff.

that they/their family member would then stay in this location until a bed in their preferred location became available.

One family's Mom was in a rehab facility after requiring a hip replacement post-fall, and their experience there was quite good. After daughters noticed that things were not progressing in rehab, they approached someone about what might happen next, and a family conference was arranged. One of the daughters had more understanding of the system, as she worked in a pharmacy that had long term care clients. The other daughter struggled with the policies and rules, as this next quote illustrates. "Yes. And that just---I mean if your parent is placed---when you live in a city and you're placed across the city, and I mean you know, and you have been the primary caregiver basically, you know I found that really, really distasteful. You know what I mean? I understand the system and my sister explained it to me numerous times, but it doesn't make it right."

At times the transition between waiting for a placement in the community to waiting for a placement in the hospital created confusion about the policies. One individual described their experience waiting in hospital, after her husband was admitted because she just couldn't care for him at home any longer. Although she had had regular communication with placement services while he was waiting in the community, no one had come to talk to her about placement once her husband was admitted. After he'd been in hospital about two months she finally asked someone if they could tell her where her husband was on the waitlist, and someone from placement then came and told her that her husband was at the bottom of the list as there was a note on his file that they had refused a bed at a particular facility. This woman said that there had been some sort of "mix-up", as she had never received a call. After she spoke up her husband was placed in a FAALO within two weeks. She wondered what would have happened if she hadn't anything?

And now [the assisted living facility] is telling us, the registered nurse there - she's the one that called ambulance - that we should be calling transition every day. And it's not---that's not the kind of person I am... You hope that the people who are working for you are doing their best and that you're going to come when it's your turn." Right. And so, do I have to call every day? Is that what I have to become now is a squeaky wheel? If that's how the system works, then I don't like it, but if I'm forced to do it to help my Dad, then that's what I guess I will have to do. And I just don't know where to go from here now. [Daughter]

Another family described a less than positive experience in what they saw as changing rules about placement between community and the hospital. Their Mom and Dad were living together in an assisted living facility, and their Mom had been on the LTC waitlist for a few months. A nurse at this assisted living facility advised them that their Mom would get a long-term care bed more quickly if she were waiting in hospital. Concerned that their Dad's health was being compromised trying to look after their Mom, they agreed to the assisted living facility's recommendation that

they have their Mom transported to hospital. Transition services in hospital apparently advised them that the placement policies worked differently in hospital. Specifically, they were told that they had to accept the first available bed, regardless of the quadrant of the city it was in. This was different from waiting in the community, where they had apparently been given the opportunity to identify one quadrant that they did not want and were told that they did not have to accept a bed there. They also learned that once moved to the first available bed, their Mom could only be put on a waitlist for their first choice. They had assumed she would still be on the waitlists for all three of their preferred choices. At the time we spoke with this family member they were trying to get ahold of the transition services worker and get their first choice changed, as they understood that their Mom would likely have to wait years to get a bed in the continuing care section of the facility where their Dad was in assisted living. This family was also upset that a nurse at the assisted living

facility, is now telling them they should be calling transition every day and they really were not comfortable doing that.

People had varied understanding about how the waitlists actually worked. That is, they were often unclear whether their family member was on a master list, or whether they were on a waitlist for a particular facility or on waitlists for all three of their choices. Understanding how the waiting lists worked seemed to be difficult period. One woman described her Mom moving from fifth on the list for her first choice (i.e., where she currently lived in assisted living), to ninth on the list. She wondered how that could happen? Others seemed to be told different things by different people.

All people understood that the FAALO in which they were currently placed was meant to be temporary, but many people described having no idea how long the wait might be for a bed to become available in the location that they had identified as their first choice. This information was described as unobtainable from transition services in some centres. In other centres placement services would give people information about where they were on facility waitlists, if they asked. For example, they would be told your *"Mom is 20th on the list"* or there are *"five people ahead of your Dad"*. They could not say how long the wait would be, however. One family member noted that when she called to arrange to visit a facility, in preparation for identifying their preferred choices, they informed her that the wait was likely three to five years. Based on this information they made the decision to not consider this facility. Others described wishing that they had been able to obtain some information about likely wait times for different facilities from transition services, in part to help inform their first choice.

"They [transition services] said because he's a veteran it could be a two-day, two-weeks, two-months or a year." [Spouse]

Many people understood that transitions/placement people had a tough job to do, as they had to work in and navigate an imperfect system, as this next quote illustrates. *"They're just going by what they have seen happen and they say well, we've heard it before or whatever you know. You know, pick three places and you're got 24 hours...they were very understanding... but their hands were tied too."* [Daughter]

What kind of information did people receive from transition/placement services

Number of choices and distance parameter

Most people were told they could select three choices, but others said they weren't given a specific number. In smaller centres, sometimes there are only a few places available that can provide the type of care required. For example, one person said that the placement person provided her with the names of the three facilities in their small city that could provide the level of care her husband required. So she then just had to let them know which one of these three facilities was their first choice. Many people understood that once they/their family member had been placed in a FAALO they were now only eligible to be on the wait list for their first choice facility.

A few, but not all the interview participants had a specific distance parameter explained to them and many could not recall if they were told about this. Of those that recalled a specific distance parameter, the distances specified ranged from 30 kilometres to 100 kilometres from their home. One person said that they had been told that the distance parameter had recently decreased from 100 kilometres to 50 kilometres. Four interview participants from one small city all said that they understood or had been told that the FAALO would be in that city.

Written information and a contact person

A number of people described receiving a brochure that contained a list of continuing care facilities, from transition services. The only information provided about the facility was the address and contact information. There was apparently no information provided in the brochure about the level of care; they had to phone the facility to get this information. Some people received no brochure or anything, but just talked to transition/placement services on the phone. This seemed to happen more frequently outside of the large cities. Interviewees recalled receiving no written confirmation of their three choices, and what they'd identified as their first choice.

"That was basically all we got, yes. So then when she went into the hospital I got a sheet saying that yes, she was in the hospital, but it was just a matter of going to be the first bed available and that was it." [Daughter]

Some people knew who to follow up with at transition/placement services, and others had no idea. Many people could not remember whether they had received any written information with a name and contact information on it. A number of the individuals who said they didn't know who to contact had family members who were placed in a FAALO from a hospital, and they weren't sure if they should be calling the transition person at the hospital or whether there was a different person they should now be dealing with. Of those people who knew who they were supposed to contact, some described having difficulty getting a hold of them, as this quote illustrates. *"I don't have her last name in front of me. Because...I tried getting a hold of her about a month ago because I wanted to know if anyone could give me an idea of like where he is number-wise on the waitlist to get into [first choice facility] and I haven't been able to connect."* This seemed to be more of a problem in large cities.

Other

Some people in the Calgary area were told that getting a continuing care bed was more difficult right now, because of the flooding. *"My wife said it's not fair that there is no choice. We understand that we were told that all the other homes were full because of the June flood at High River...but that's what I was told, so we had no choice."* [Nephew]

In summary, there were both commonalities and differences with respect to people's understanding of the policies, and what they had been told. There were differences not only across the province, but also within the same city/town.

3. Selecting a preferred location

Identifying choices

Most family members, and some residents, recalled that they needed to provide their three preferred choices to the transition worker, but that once they/their family member were placed in the first available bed they were only put on the waiting list for the one facility that they had identified as their first choice. Many people described being rushed in making their choices, with little time to go and see facilities in order to help inform their decisions. This seemed to be more of an issue in bigger cities where there were a number of options. In towns and small cities, people were often familiar with the options that were available.

"I found it frustrating because you're told---you go around and you pick three places and you're told well, she probably won't get there, which is fine, but nobody talks to you...We only had 24 hours to do this too....We had to do it very quickly. Unfortunately enough my sister was with me to be able to do this, because she lives out of town and it's not as easy for her to just come on in, right." [Daughter]

For people living in large cities being provided with a list of all the facilities and asked to make the choices quickly was often described as challenging and/or frustrating. Many people described being somewhat overwhelmed with providing care in the community, and/or supporting their family member in hospital, making it difficult to arrange to visit facilities, as this next quote illustrates. *"Yes. I had a whole list of all the places that were accepting. And I sort of went through ones that were relatively convenient... And yeah, I didn't really know where to begin, but anyway...in hindsight I thought oh,*

maybe I should have called this place or maybe I should have called that place. But as I say, it was quite a rush to give her my choices, so I didn't have a lot of time." This woman was working full time plus spending time daily with her husband in the hospital, not leaving a lot of time for anything else. In another case a nephew described how hard it was to go out and visit places while he'd been caring for his aunt at home. She was now in hospital awaiting placement. *"I didn't have a chance to get around [to physically visit all the places]. 'I've been doing night shifts and all my sleeping time went into her major care. But having details to look after... and those details was pushing my sleeping minutes. I was not able to function, so I didn't have time to do those things."*

A number of people wondered why they were even asked to provide three choices, as when once they got placed in the first available bed they were put on the waitlist for their first choice only and it seemed unlikely they would ever get placed there. This perspective was most commonly heard from people living in a large city where there were a large number of facilities. Many family members said they wished transition services were able to provide more information about the different facilities and more help with selecting their three choices.

Key factors influencing the selection process

Location

The location of the facility was the main contributing factor to placement choice selection; that is, almost everyone we spoke with started with the location of the facility as the main factor influencing their choices. Even those residents who could not recall having made a choice said, when asked what was most important to them, they said remaining close to family and friends. Location was most critically important when there was a particularly close relationship between the future resident and a family member. This most often was a spouse, but not always. For example, in one case a daughter had been living with her mother for some time,

and over time had quit her job to provide the 24-hour care her mother required. Many spouses were also elderly themselves, which in some cases made it difficult for them to get around. Others were trying to consider how long they would be able to drive, themselves, as this quote illustrates: *"The reason we're choosing---we're looking at these areas is because I'm also a senior and I'm looking at the care and also the availability for me to get there... So we decided to stay with the ones that were close for me because I am 80 myself. And how long am I going to drive?"*

Although many people usually select their preferred choices initially based on location, the relative importance of location often changes after they've actually had the experience of having their family members living in a facility. After location, people described a variety of factors that influenced their preferred choices. These included: the quality of the care provided; the feel of the facility; physical environment; cleanliness of the facility; security; the activities available; and the food. These are each briefly described here.

Quality of care

It wasn't until placement in a FAALO space that many people reflected on how important the kind of care provided was, and how difficult this is to assess ahead of time. Some people knew others who had family members in a particular facility, so could ask them their views on the care; but often it wasn't until their family member was placed in a facility that this could be evaluated. In a number of cases the care provided moved up on the list of importance, before location, as this next quote from a daughter illustrates. *"The kind of care that they give to the patient. I mean that's the number one... You know, me and my brothers, like going to see her and everything, it could be second; but I think the number one is the kind of care that they receive in the nursing home."*

"Yes, they do genuinely care and as I say, I go at different intervals of time and Mom is always immaculate. You know you can tell that her teeth have been brushed; you know the daily needs have been met for sure." [Daughter]

The kind or quality of care provided was described very broadly by the people we interviewed. The health care, the personal care and the relational care were all described as being very important. The term relational care is used here to mean treating a resident in a personalized and human way. A number of people described how important it was that the people

providing direct care to their family member genuinely cared about them, and treated them as a person. In contrast, people were very upset when this dimension of care seemed absent.

One family [two daughters] talked about how they tried to judge quality of care when touring facilities to select their preferred options. *"Well, just---a couple of times we talked to some of the nurses or the care aides and stuff. And you know, you could tell. They were around, so they would talk to them, but that was basically---I mean again you're just doing a walk-through. Just trying to generalize and okay, this looks pretty good. Like it is a generalization, because you don't know for sure until you get into a facility. Like I mean where Mom is now [FAALO], the care she's getting is absolutely incredible."* Many people, when asked about whether they considered the quality of care being provided when trying to make their choices, including what some people called the *"feel of the facility"* under quality of care.

Two individuals interviewed whose family member was placed in the small local hospital's long-term care unit were very happy with this location. In addition to proximity, it works well as they know and trust the people that work there, and that doctor is right there. They knew that their family member is receiving excellent care.

"Because its small we knew she would receive excellent care; the doctor is right there... [Son]"

Feel of the facility and physical environment

"The part of [facility] that I really like is it's an older building and it's got a really homey atmosphere there. And there's activity; you can see people walking. He's got a fantastic window that he sees outside and he sees grass, he sees cars. He's not located somewhere on a fourth or fifth floor where he just sees roofs. They've got cats walking around. There's a dog...Sometimes you know, fancy isn't always the best." [Spouse]

Homey was a descriptor used by a number of people to describe what they liked in a facility.

When asked what they meant by that, people described a number of things such as: being able to open the windows; having room for personal effects and lots of

places to put photos; lounges and places to relax outside of our room; ability to see and go outside; having cats and/or dogs in the facility, etc.

Some people commented on specific physical features of a facility that they liked and why. For example, one family described how they liked the design of a FAALO facility that their Mom was placed in. *"And one thing they do have going for them is they have---instead of having a closed desk nursing station, they have an open, round table and there are the nurses and the aides and the patients all sitting around."* For a few people, having a private room and/or at least equal access to space and light was critically important, as this next quote from a nephew who was most upset that her aunt was placed in a double room indicates. *"The one thing is another person should not be living in a quarter of the room and only can see the back of the wall and a hallway and a toilet basically and nothing else. And the curtain is right across the room...the one by the window has more space and a place to store it. And there's a big window to see through, which is really good. The other person has---I don't think there's any hope left in that person."*

Another individual, the daughter of a resident, talked about how nice it was to have an assisted living facility attached, as this next quote illustrates: *"And it's attached to assisted living and often I noticed that usually the men are in full care. I've noticed a couple of men in full care and the women live in the assisted and they walk over and it's all inside...And they can come and help feed them or whatever they need. And they're kept together."*

Food

"You eat the same thing all the time and it kind of gets boring. Nobody uses the saltshaker, so the oatmeal is really bland. But you've got to cook for everybody, so I mean I eat what I like and I don't eat what I don't like. Well, when you have to cook for a large amount of people it's okay, but when I go out for lunch or out for dinner I sure enjoy it." [Resident]

Food was often not spontaneously mentioned as a high priority, but people did comment on it when asked about it. The lack of choice was described as a reality by a number of people. Residents in particular talked about the food as something that contributed to their quality of life. Almost everyone recognized, however, how challenging it was to cook for a large number of people with different needs and likes.

Prior knowledge and word of mouth

A number of people stated that prior knowledge of a facility, either because they knew other people living in a facility and had been to visit them there and/or they knew from 'word-of-mouth' the reputation of the facility, influenced the selection of preferred choices. Some families already had

"Well, we went around and some of them we already knew, just having looked at different facilities when we were trying to get my Mom into assisted living. And so, some of the places we chose already had assisted living plus long-term care and dementia units and everything." [Daughter]

some familiarity with the various facilities out there, as they had looked at a number when helping their family member find an assisted living facility, and in many of these facilities there were also continuing care sections.

A good fit

"The possibility of [facility] was another one and it's actually closer for me, but I found it was very cold. It's very new and very sunny...but to my liking and knowing my husband, I think he'd really feel isolated there and that would be even worse. I think he needs to see activity because he can't really do that much himself." [Spouse]

Finally, selecting a facility, and the specific factors that were most important, was often a very individual thing. People were looking for a facility that was a good fit for the resident. Family members often talked about trying to think about what was going to be most important to their loved one at this time in their life. Some people were conscious about how it could be a bit of a struggle to keep their personal preferences out

of it.

One family, for example, talked about how social their Mom was, which meant that finding a facility with a lot of social opportunities that facilitated interaction between the residents was very important to them. This applied to people's preferences for private vs. shared rooms as well. Again, a family whose Mom was very social, noted that they preferred a shared room for her over a private room for this reason.

Another family said that they had always been very "outdoorsy people", so her first choice for her husband of the three facilities they had could provide the level of care her husband required in a small city, was a smaller facility situated on an acreage just on the edge of town. Being able to take her husband outside in the FAALO was important to her, as this quote illustrates: *"And then the weather is going to warm up and we'll put him in a wheelchair and take him outside and walk him around outside here. And there's a pathway and you can walk over behind and there's open prairie with horses and so on...we're the outdoor type of people. That is why I picked [other facility] because it was more our type."*

4. Moving to a first available bed (i.e., to a site other than the first choice)

Accepting the first available bed

All the people we spoke with who did not get one of their preferred choices felt that they had no choice but to accept the first available bed, regardless of what they thought about it. Some people said they had to accept the FAALO as they were unable to provide the level of care their family member required at home. No one was informed about any type of appeal mechanism, and no one tried to get the decision regarding location changed. One family successfully advocated for their family member to stay in hospital an extra week so that they could obtain what they felt was needed rehabilitation, before moving into a long-term care bed.

"I was told that there was no---I had no choice. And she would be moved whether I agreed to it or not.... They just phoned and said that they would have a transition vehicle there for ten AM on Tuesday and this was on the Monday that I got the phone call. And that there was no choice." [Daughter]

But they basically said that I have to go here. Like that's why---like I might have wanted to wait and go to the other place, but that wasn't an option. It was go and if you don't like it you can move. That's kind of what was said...I mean obviously this is where the beds were available and that, but it was kind of an emotional time. You know losing your freedom for lack of a better word. And then it felt like I was being imprisoned. That would be as close of a thing as I could say. You know that you're here and there didn't seem to be any sensitivity I guess. But then maybe it's like ripping the Band-Aid off where you get her done and then it's okay. Which is what happened to me."
[Resident]

One younger woman who was assessed for placement and provided her choices learned that same week that she was moving into a facility that was her second choice. She doesn't recall anyone talking to her about needing to accept the first available bed. This young woman said that she gave them her two choices of where she wanted to live, before they could tell her about her options, as this

quote illustrates, with the most important thing to her being in the community where her church was located. Her first choice was the newer facility of the two.

Families waiting for a bed in the community were also told that they had to take the FAALO, or their name would come off or go to the bottom of the list, as this quote from a daughter illustrates: *"And so, I mean they told me you have to take this. Like it's the first bed and you take it you know, otherwise she's off the list..."* Once again, everyone we spoke with did understand that they were waiting in the 'first available bed' facility for a bed to become available at the facility they had selected as their first choice or one of their three choices. No one had any idea of how long that wait might be, however, and some people feared that they/their loved one would never get moved to their chosen facility.

Being supported through this transition

Many people talked about moving into a continuing care facility as being a tough transition for both residents and family members. A number of people described getting very little notice that they/their family member were moving to a facility, and this created both instrumental and emotional challenges for some. One family member whose Mom was waiting in the community for a bed, received a call from a facility on a Wednesday saying they had a bed available and they could move her Mom in on the Friday or the Monday. They moved her in on the Monday as the daughter had to make the arrangements for handi-bus to transfer her from home to the facility.

A younger woman talked about how she really had no idea that she was going to be placed so quickly. In part because she got mixed messages from physicians, with one saying she still needed some rehabilitation before being moved into a long term care bed. This next quote describes her experience.

"I got in here so fast there wasn't really much time to think. In fact, it shocked me because the doctor came in and said that I was here and that they were going to take me to rehab and once I was done doing some things in rehab, then they would place me. And then all of a sudden they came up one day and said oh yeah, we've got a place available for you, you're leaving on Thursday. And this was I think Tuesday at noon. Boy, it was a shock. I was quite disconcerted I guess would be the right word... No psychological preparation whatsoever...I'm just lucky I got in a good place. If I'd have gotten a bad place or a place that I didn't fit in that would have been hard." [Resident]

A number of people had never heard of the facility that they or their family member were being moved to, and sometimes with only a day's notice that they were being moved, didn't get an opportunity to see the facility before the move took place. People commented that the transition itself is difficult, and then when you are moved into a facility that you know nothing about and didn't choose, it can be an emotional time. One daughter described asking for some notice before her Mom was going to be moved to a FAALO; she learned on Friday that their Mom was being moved the following Tuesday, and that was sufficient notice for them. *"They gave me enough notice I could be up there and be with her. I asked them for that and they did that."* One individual explained that one reason that she reacted to the move a little better than her sister, was because when she was working in a pharmacy they did the medications for the facility, so she knew it. Being aware of how much notice you might get, getting as much notice as possible, and having some knowledge of the facility ahead of time contributed to making the move more acceptable.

One family was quite upset when their family member was moved into smoking facility and placed in a double room with a smoker. The spouse said that she had no idea it was a smoking facility, and that there was a possibility that her husband could be sharing a room with a smoker^v, as this quote illustrates.

"The only time we had an issue was when he was transferred from [hospital] to [facility]. He was put in a room and he had to share a room with another gentleman, who was a heavy smoker. And I really got really upset because my husband is not a smoker and he has lot of health issues. And he didn't need to have to deal with that too. So I made a little bit of a stance and they did move him into another room." [Spouse]

Some people described being extremely frustrated, as they had put a lot of effort into selecting their three choices and then didn't get any of them, as this quote from a daughter illustrates. *"I was extremely frustrated. It was very emotional, because I really did have my heart set on the three that I picked... When I had heard [where she was being placed] my husband drove me up there because I'm a very nervous driver*

^v A staff member, in an informal conversation, said that she felt transition services should collect information about smoking ahead of time, and not place people who are non-smokers in shared rooms with a smoker.

person you know. That was an issue ...and I went in and I didn't see anybody engaged and I went in on the weekend and you know, I didn't have a tour or anything. I just kind did a little bit of a walk-through. I wasn't happy about the decision at all. But then again, you can't judge a book by its cover and I knew that. So I said just settle down and let's just see what happens. You know you have to be realistic too. But yes, I wasn't initially happy at all."

In many cases people had very little or no support through this transition. Many family members also spoke about the transition to the FAALO as being difficult for the resident, and they described their efforts in trying to support their family member through the transition, as this quote from a spouse illustrates. *"I had to be there all the time, just to make him feel that he wasn't abandoned. But then after I started to not visit for as long, and I tried to get him to get used to the place and the people there. Every time I came he was packed. He was packed and he'd pack everything, so I was getting a little smarter and he only had clothing for two days. And now he's kind of stopped the packing, but they say that he gets anxious and this is what he does."* In a number of circumstances people had a number of moves in a fairly short period of time, and this was also described as difficult for people and in particular as they get older.

"So those transitions are difficult you know, when they age too. You don't want to be moving them a hundred times." [Daughter]

Experience moving to a FAALO

The majority of the people we spoke to had moved into the FAALO within the past few months, and some within the previous two weeks. The actual physical move to the FAALO went smoothly for all the people that participated in an interview. Most of the people we spoke to had been transferred either by an ambulance or handi-bus, and this had been organized by the hospital. A younger resident talked about how she appreciated her son being able to accompany her on the handi-bus from the hospital to the facility. She also described being a little bit overwhelmed on the move day, as this quote illustrates.

"Oh, I got a little overwhelmed because of course they take you in and they set you down and they tell you everything and they give you everything and you're kind of going huh? If fact, my son just told me something that I had forgotten. And they had told us that day and I just didn't remember. But they explained the place and they told me what time dinner was and like all the stuff you need to know when you're moving in."

People had varied experiences at the facility where they/their family member was placed. Many people described being quite happy with the FAALO placement once they/their family member had settled in, which often took a little while (i.e., at least a week). Factors that influenced family members and residents' experience with the FAALO very much mirror the factors described earlier in section 3 – "Selecting a Preferred Location. The quality of care provided, communication with family members, the activities that residents were engaged in, the feel of the facility, and the physical surroundings were all described as contributing to positive and negative experiences. The series of quotes below illustrate these points.

"They communicate with us about everything. Nothing---they see you in the hallway and they say oh, when you've got a minute I need to talk to you to say oh yeah, yesterday your Mum did this and this and that...The communication is awesome, so I really can't---like I say, it's an older facility, but the care she's getting is awesome and I'm really quite happy." [Daughter]

"Yeah, I was real happy with their care as well and they also had a chaplain that went there and they had a church service. And he would always around to the people's rooms and check on them, you know? That was nice; that is important to them. And the other thing was remembering their names." [Spouse]

"I like the activities...I'm in the hand-bell choir. We did concerts this Christmas; went around to all the other floors and played our little hearts out...We're not good, but we do have enthusiasm...And then they have a ladies club and I go to that. And they do music and sometimes I go to that. But I also am computer literate, so I have my laptop and my iPad and my TV, so I'm quite content in my room as well." [Resident]

No one we interviewed who was currently placed in a FAALO had received any follow-up from transition services to date; they had been waiting a range of one week to a few months^{vi}. In a few cases, where people knew who to contact, they had followed up with transition services on their own. Many had been told that transition services would call them when a bed became available in their first choice, but really had no idea whether to expect that call (i.e., whether it would be in a few days, weeks, months, or years). As described previously, some people did have a name and contact information of someone in transition services to follow-up with whereas others did not seem to know whom to call to check in with.

Most of the residents we spoke to seemed to leave the communication with transition services up to their family members. One younger woman who took responsibility for her own health and care said that she hadn't heard anything about a bed coming up in her first choice facility, or heard from anyone at all since she was placed. In response to a hypothetical question about what she would have done if she had been placed somewhere that was not one of her choices, she stated: *"So if you had placed me in another home I'd probably still be there, because I wouldn't know how to get out. See, here's the other thing. Do I phone the ladies at the hospital that placed me here? That would be my first inclination or do I phone someone else? I don't know. So if you're deeply unhappy, then where do you go?"*

The people that were really struggling with the FAALO were doing so because they felt it was a poor fit for them. In some cases people had concerns about the quality of care, in others it was the physical environment and/or the cleanliness of the facility, and yet others because of the location. Placements that make it difficult for spouses to see their family member, for example, were described as very hard for families. Difficulty traveling to visit a loved one can be particularly challenging for elderly people with their own health issues. These individuals may no longer be able to drive, and taking public transit can pose huge challenges when mobility is restricted and/or vision is poor. These challenges are compounded in the winter. As one daughter said about her father who is living in an assisted living facility the other side of the city from where her Mom has been placed and he insists on spending time with her daily: *"He has to walk to the bus a good fifteen minutes and then, now when I Google to get to [FAALO] it is an hour and forty-five minutes just on one bus to*

^{vi}This was collaborated through informal conversations with facility operators and nursing staff at two facilities in a large city, who stated that in their opinion transition services could keep a closer eye on people post placement, when they are waiting for a bed in another facility. Right now people feel they are being "dumped", as there is no follow-up by transition nurses.

get to [neighbourhood] where this place is. And then it's the same thing back, so in the afternoon if he goes, he's three hours just in travel."

One family describing having a great deal of difficulty with the physical environment in a particular facility, concerned about how dark the rooms were, and the overall lack of cleanliness. They said the nurses were lovely, but just couldn't deal with the facility itself. *"The nurses---pointing at the number one thing; the nurses are excellent. They really are sweethearts and professional. My wife [niece of resident] is an elderly caregiver, but she is from Hungary and she doesn't---a place like that is not where an elderly person should live for the rest of your life....Its heart crushing."*

Another family had an experience where they saw another resident in a facility treated inhumanely which really shook them up, and this was a major contributing factor – in addition to their general dissatisfaction with the care being provided and their Mom's unhappiness – to making the decision to move their Mom back home. She felt that many of the people working there were doing it because it was just a job, and not because they had any compassion for the people they were looking after. Her Mom had some complex care requirements, which in her view the staff were not able to handle. She also felt that they were also understaffed for the level of care that the residents required, so thought that was a contributing factor to the poor care. They described their overall experience with the care being provided quite negatively. In addition, their Mom was not a very social person so she was not happy being in a facility with so many people. In another case, the family similarly described the FAALO as not being able to provide the level of care that their Mom required.

"If they're going to do this kind of job they need to have a little more sympathy for the older people. They're still humans you know and you cannot just---just because they're like---some of them don't understand anymore. Like they treat them like animals you know...?[Daughter]"

Ultimately, families and residents identified different factors that were important to them in a supportive living or long term care setting. It was when people had clearly defined needs or expectations, and these were not met in the FAALO, that the experience of moving to the FAALO was most difficult and was described in the most negative terms. This lack of a good fit with needs and/or expectations contributed to the sadness, sorrow, angst and distress that is described in the literature^{vii} as often characteristic of the transition to a continuing care setting.

5. Moving to a chosen site

Moving from the first available bed to a chosen site

At the time these interviews were conducted, people had been waiting in the first available bed from a period of less than a week to three months. None of the other residents/family members interviewed had moved yet from the first available bed site to their preferred site. People had a variety of views on whether they would move when a bed became available in the facility they had identified as their first choice. People who were very unhappy with the facility where they/their family were currently placed, either because of

^{vii} Refer to the literature review done as part of this policy review project.

location or because of characteristics of the facility itself, said they would move as soon as a bed become available.

A number of people had already made the decision to stay where they were; that is, not move into the facility they had identified as their first choice. For many people, making this decision was difficult, and they described weighing a number of factors. Refer back to section 3:

"I'll tell you right now that we aren't moving her. No, we're very happy there and she was so confused and mixed up as to where she was. It's not fair to these dementia people...moving them around all over the place. They have no idea and that facility---like she's only been there about a month, lots of staff and well organized and I've been very pleased [with the care]." [Daughter]

"Selecting a preferred location" for the many factors which families considered. Many family members, for example, struggled with moving their loved one yet again if they had settled in quite well to the new facility and if family members were satisfied with the facility and the quality of care. They often described balancing proximity to where they lived with the disruption caused by another move.

One family member, a spouse, for example had very mixed feelings about whether to move her husband. Although currently he is still on the wait list for their first choice, and she said they would move him there if a bed came up fairly soon, as the first choice facility is nicer in that it is more modern and her husband would have a private room. There are different perspectives among the four children, however, as to whether this is a good idea or not and she described herself as being torn as this quote illustrates: *"You know it's really hard to know. Sometimes I go there and I think he really is quite happy here, and do I want to take him out there and put him in a private room where he might feel alone. And is he going to know how to press the button for the elevator to get down? You worry about all these things."* Many people described trying to determine what was important to the resident, rather than themselves. Being able to get to travel to the facility to visit, however, was still an important consideration.

Some family members felt strongly that once their loved one had settled into a facility it just wasn't right to move them, even if it meant that they would not be able to visit as regularly; that the window of opportunity from moving from a FAALO to a chosen facility was very short, as this quote from a daughter illustrates:

"I'm not going to move my dad now. Had he gone into his first choice right off the get-go or not even his first choice, but his second or third choice that would have been great. But you know, I can't move him now. It's beyond time you know? He's gotten used to it and he's used to the way the people deal with him there. He's got some familiar faces, so you know the time to do it is from the hospital and making that first transition and not after the fact."

The strength and type of relationship that the family member had with the resident was clearly a strong contributing factor in this decision-making, and trying to weigh these trade-offs.

"And I'm going to ask maybe the doctor to contact them because sometimes when it's a medical physician calling them they act a little more faster than an individual... And like I said, I want to keep her home as long as I can. Even if I can get some help, like just even at least for a couple of hours two times or three times a week that's good for me you know. Like I'm not a party person and I don't go out. I'm more like a home person; so I mean just to get out and go grocery shopping and if I have appointments. That's good for me." [Daughter]

One family had the experience of moving their mom out of a facility back home, after she had spent ten days in a FAALO. Then when the daughter followed up with home care to try and get that restarted, the homecare coordinator that had been looking after her Mom's care

said that her Mom was no longer on her list. The daughter was just waiting to get a call back from someone in homecare. If she hadn't heard back soon; she'd been waiting a couple of weeks she was going to see if her Mom's physician might call.

Like family members, some of the residents were not planning to move to their first choice facility, and others were. Those residents who were planning to move wanted to do so because they wanted to be closer to family members. For example, one woman who was placed in continuing care wanted to move as she felt it was just too far for her husband to travel every day to see her. He tended to come every day and bring her home for supper, but had to travel across the city to do so. Another resident said that she had pretty well decided to stay where she was, although she initially had not been very happy with her placement. She had gotten to know the residents and staff, and liked her roommate. Although she described the care as not great, she felt that due to the lack of staff in continuing care facilities the care was likely to be the same (or even potentially worse) regardless of where she was placed. The FAALO was also reasonably close to her son and grandson, who visited her frequently. A younger woman described her experience of moving into the facility she had designated as her second choice and deciding to stay there. She made that decision after about two weeks in the facility, primarily because she was getting great care, she liked the feel of the facility, she was involved in some activities she liked, and had she felt the staff there liked and cared about her.

"When I got here they said I could change if I wanted to, but then I got here and I got settled and that was it. I've moved three times in the three months I've been here until - I got the proper room. But like I said, the care is top-notch as far as I'm concerned...See, I don't feel like I'm sitting here waiting to die...I don't feel like I'm a bother to anybody..." [Resident]

Moving directly to a first choice

In four of the 18 interviews conducted, all in small towns or smaller cities, the resident had been able to move to the facility they had identified as their first choice. Families and residents who had this experience described feeling incredible relief when they learned that a bed had become available in the facility they had chosen. There was often still considerable anticipatory stress and worry, while they waited to learn where they/their family member would be placed. So in this respect, the waiting part of the experience with the feelings of uncertainty and lack of control was no different from what was described above. Also, the transition from living in an assisted living environment or with a family member is still challenging and settling into the chosen facility does take time. These people described the process *"as positive as it could be"* given the inherent difficulty of this transition.

In all of these cases, people described being appreciative of how people in the hospital worked with them to try and get a placement in the facility they had selected as their first choice. In one case, a woman with complex medical problems absolutely did not want to be placed at the continuing care centre where she used to work as an aide before becoming ill. She did not want her former colleagues providing her personal care. Her daughter was very concerned that if she were placed there it would have negatively affect her mental health. Her Mom selected a facility that had a younger population and where there was more independence, as she was only 64, and she very relieved that she was able to move there.

The main difference in these experiences was that people felt that they had some say in the process, that they had been listened to and their wishes had been taken seriously; that healthcare professionals had worked hard to get them placed in the facility they had selected as their first choice. As one family member said, whose Mom was placed in a continuing care bed in their small, local hospital: *"It went very smooth for us and we've happy about that... I think them considering what family lives there, I think it's a good thing."* [Son]

6. Processes and policies that would work better for residents and families

After listening to people describe their experience with placement in a continuing care facility, and the related placement policies and processes, we closed the interview by posing two questions:

- If you were making the rules that determine how people get placed in a continuing care facility, what would they be?
- If you had to go through this process again, describe how you wished it would go?

When asked directly how they might change the policies or rules around how continuing care placement worked, most people said they found this a difficult question to answer. **Almost everyone we spoke to said that they understood the need for some kind of a policy;** more specifically that people could not wait for long periods of time in hospital bed for a long term care bed in a preferred location to open up. Some people said, in response to this question, that they felt lucky and relieved that the FAALO they/their family member was placed in wasn't even further away from family or even in a different town or city. The following quotes illustrate how accepting people in general were of the policy, and this included people where the placement had created great hardship for them.

"Well, you know I'm kind of---I look at it two ways. If I was someone waiting to get a bed and I'm in a hallway without a bed and you turn down a long-term facility, I guess there should be no choice in that really. Unless we're going to build more hospitals and have the luxury of that, because I think our hospitals are packed right now. And so, yeah, maybe you should have to go, but I still think you should be able to keep your three and move forward in that way and not lose the three choices. And maintain your status." [Daughter]

"You know that's really hard to say. They want to move these people out of the hospitals, because there's always somebody waiting for a hospital bed and I think you don't really have much choice. If they feel that the patient is well enough to be moved and they still get full nursing care, I think that is the way it has to go. They have to---if I waited my husband to go into the Colonel Belcher, he'd be in the hospital forever." [Spouse]

"You know, I'm not sure there's any correct answer for that, because again, having worked in long-term care, I know being on the inside looking out, I know what happens. And so, I don't know what the answer is to that one because it's been this way for years." [Daughter]

"Well, I don't know. I guess in my case I could have got some place that was in High River and I didn't. Yeah, I'm just happy that---yeah, I got it as close as I did. I don't know. Yeah, I can't really answer that." [Spouse]

"In theory I understand there might not be a room available and you don't want someone in the hospital using an acute care bed but we still need to take this into consideration - need to think of the person's mental wellbeing as well as their physical needs." [Daughter]

Yet the current policies can create great hardship and sometimes heartbreak for people, so some people did have some suggestions regarding how the policies might be changed, and/or in how the processes might be improved so that they work better for residents and their families. These are outlined below.

When asked specifically about the distance parameter

dimension of the policy, a number of people living in a large city suggested **being able to identify a smaller geographic location within which they have to accept a first available bed**, as these quotes illustrate.

"Given that it's very difficult to move people once they're settled somewhere, would it make more sense to you if you could just choose a quadrant of the city?" [Daughter]

"I wish it [the 50 kilometre rule] was different. I think that's really hard on patients and the family because like he could be placed in Strathmore and nobody would visit him. It would be great if they could sort of segregate the city and like if you're from the southwest---but I don't know how that's possible. [Spouse]

"I think that would have made a hundred percent difference [if we got to pick a quadrant of the city for the FAALO]. I mean like I say, we consider ourselves fortunate because that did happen to us. At least we got southwest." [Daughter]

Others felt that the distance parameter dimension of the policy created greater hardship in some situations than others, and that **individual circumstances should be considered in the placement process**. There should be priority, for example, on ensuring that a placement won't make it difficult for spouses to see each other, as this quote illustrates.

"I think that should be a higher thing to think about if they have a spouse that's in another facility, they should kind of have priority at being at one closer to the other spouse. Because I think that's very hard on them to be put in different facilities, I guess if they're still getting along, right?" [Son]

Residents/families require more information, support and time to identify their preferred choices, as the two quotes below illustrate. People describe often not knowing where to begin and/or what to look for. They would also appreciate getting information about relative wait times at continuing care sites, as this kind of information would influence their decision-making about their choices. This is particularly important if people can only be placed on the waitlist for their only first choice (i.e., not all three choices) once they've been placed in a first available bed.

"Maybe if we'd been more informed, I wouldn't have been so stressed...the girls at [rehab facility] were really good, but they could only give us so much information too..." [Daughter]

"But I don't understand all these lists and that was how it was. Nothing was ever really properly explained to us. And I think every family should be given a sheet or a chart with all the different levels of care...So that would be my recommendation is to have a package done up, so that caregivers know where they stand." [Daughter]

A number of people also wished that transition/placement services people could play a more active role in providing this information and helping people make a more informed choice about what facilities would be a good fit for the care they/their family member requires. Yet other people felt that the transitions/placement person was primarily focused on placement, and that it would be good to **have an advocate to support the person through the transition, and to ensure that their interests are looked after**, as this quote illustrates.

"Yeah. And somebody---like when you have a placement office your big thing is getting somebody placed. If you're [facility], you want to get somebody placed in your facility. It would be nice to have somebody

who was your advocate and not just somebody for the facility or the placement if you know what I mean. Somebody to look out for your interests.” [Resident]

Information on how the different programs and benefits work was also described as being a good thing to add to an information package, as this quote illustrates.

“The other thing that’s unclear is how the system works as far as---like if you need a walker or if you need something done or fixed or whatever. I never understood how many of this stuff worked according to her income and her Alberta Seniors and all these things. That should be written down how you qualify for those things...I said to my husband, well, that’s the difference between Aids to Daily Living and you’re allowed this amount and Alberta Seniors? Or if your income is over this amount you don’t get this, but you qualify for 25% of the drugs. I don’t know how it all works. So that would be a very good added thing to be in the package. Because that was a---every time I turned around I had all these questions to ask them.” [Daughter]

Some people wondered why they were asked to provide choices, as based on their experience it seemed unlikely that you are going to get one of those choices. This seemed to be the experience of the people living in a large city. If you are asked to provide three choices, and it would only be a short time for a bed to come up in one of them, it would make more sense to wait until a bed became available there, given how difficult transitions can be for older people.

People who had family members waiting in the community for placement had difficulty understanding why the FAALO applied to people waiting in the community for a bed; that is, why they could not wait for a space in one of their three choices to become available, as this quote illustrates: *“And I know if you’re at the hospital they do that. But if you’re at home I think that you should have more of a choice.” [Daughter]*

Getting as much advance notice about the move into a first available bed, so that there is opportunity to go and see the facility beforehand, and begin to prepare for the move.

“I wished that I had had some advance warning. And maybe they said it and I didn’t realize it, but you know, like the one doctor who kept saying we’re waiting for placement and then another doctor said we’re going to rehab. I know a few of the people when they’ve come in that since then they’re upset when they get here and I don’t know---I kind of tend to think it’s because it hasn’t been really explained to them, but maybe it has and they just don’t like it. But there was a lady in here who had TST like I did and I just felt that she was kind of like me. They said she only had one day’s notice, but that’s hearsay of course. But she was upset too. I don’t know if there’s any way you can make that better or not.” [Resident]

Being able to move from one level of care to another within the same facility was described by some as ideal, but now seemingly impossible because of how the waitlist policies work.

“Because we had heard from a friend of mine whose both her parents went to the [facility] when they opened and they went through the whole system over there, according to as their care levels changed.” [Daughter]

“I often thought that it’s too bad I couldn’t just have moved him from the assisted living down the hall and into another corridor, which was the Inter-Care.” [Daughter]

Finally, although most people recognized the challenge of balancing the need for hospital beds with trying to place people in a place of their choosing, **they stressed the importance of trying to keep some humanity in this process**, as this quote illustrates: *"These are not just a number – they are actual people." Regardless of how old they are they have friends and family. It is hard for them to give up their life too as well as the accommodations for their physical wellbeing.* [Daughter]

7. Other comments and suggestions

When we asked people if they had anything else to say that they hadn't yet had an opportunity to share, there were a few issues described that were related to but perhaps not immediately or directly applicable to the continuing care placement policies. These are summarized below.

Many people stated that we really do need to start building more continuing care facilities, as the challenges being experienced with the current continuing care policies are only going to get worse as the population continues to age.

"Oh, that's the one thing that I would have to say is that there are more needs than there is staff. At certain times, like everybody has to get up in the morning by nine because that's breakfast and they just run... And it's not that the people here aren't doing their jobs, because they're just running. Like after mealtimes is always a busy time getting people up and getting them to lunch and then getting them back." [Resident]

"And unfortunately it's going to get worse and you know, the government needs to fund these homes because I mean we're going to have an influx of seniors and no place to put them." [Daughter]

A number of people commented on how short staffed many of the facilities were, and felt that the government should perhaps look at how these continuing care facilities, particularly as it seems that people who are being placed in these facilities seem to be have

increasingly complex needs.

The frequent moving to different levels of care, as once someone starts to deteriorate their care needs seem to change quickly – was described by a number of people as hugely difficult for both the resident and the family. In a few cases it seems like their family member deteriorated while living in the community (assisted living or family home) while waiting for an SL4 spot to become available, and then they deteriorated rapidly and required placement in a full care bed (LTC), leading to multiple moves in short periods of time.

A number of people described having to be pretty strong advocates for their family members in order to get them the level of care they required. They actively worried about other families who may not have the ability and/or opportunity to advocate as effectively; for example, families who do not live in the same town/city/ or province, and families who are poor and/or struggling.

More than one person described having to fill out involuntary separation forms, to be legally separated, in order to get more benefits as being very difficult to do. They wondered why it has to be that way. Health and related professionals did try and explain that it's just a separation *"on paper"*, but the spouses who spoke about this said that it just doesn't feel right when you've been married for more than 50 years to have to do this.

Finally, a number of interview participants, both residents and family members, did mention how much they appreciated being asked to participate in an interview as it gave them an opportunity to be heard.

"And actually I really appreciate this interview because you know, it kind of makes me feel like my voice is being heard." [Daughter]

Key findings and concluding remarks

A key finding from these interviews with family members and residents, is that people understand the necessity of moving people quickly out of rehab and hospital beds, so others requiring care could move into the beds. So the necessity of having a FAALO policy of some kind is understood, but there is hope that it's possible for Alberta to come up with a better way of actually operationalizing the policies. Some people did wonder why FAALO policies were in place for people waiting in their home in the community for a placement, however. There was also some confusion about how the waitlist policies worked in the community, and how or if the rules changed if someone moved into hospital waiting for placement.

Another key finding is that people have different needs and wishes with respect to a continuing care placement, meaning that a 'one-size-fits-all' policy creates difficulty for residents and their families. Having some kind of appeal process when the first available bed could help reduce placements that are likely to create great hardship and/or anguish for residents and families. Maintaining relationships and connections with family and community were described as important factors to consider when placing people. This was described by a number of people as being particularly important when a placement would affect the ability of spouses to see each other.

Most people described their interactions with individuals from transition/placement services are good, and a few people described these health professionals as very caring. Their perception was that these health professionals are struggling to work in an imperfect system, however, and that they are often under-resourced for the role they are supposed to play. **What works well for patients and families is when healthcare professionals listen carefully to the wishes and needs of residents and their families.** At times assumptions are made about what is best for residents and their families; although well intentioned, they may not take into account the values, beliefs and wishes of families.

Many people want to keep caring for their loved ones at home, often, until the very last minute. If the family waits to the very last minute, however, it can take too long to get a bed and the caregiver's health is put at risk. Yet sometimes families will put a family member on the waitlist, and the bed comes up instantly and they are just not ready to accept the necessity of a move. **Residents and their families describe how much they appreciate being able to work closely with someone who can help make truly informed choices that meet their needs.** There were examples of these kinds of positive experiences described by these interview participants, many of them taking place in smaller towns or cities.

There is some tension between location and the quality of the experience at the facility, when trying to decide whether to move family member from a non-preferred option to their first choice facility. If a resident is happy in the facility, the care is good and the staff knows and treat the person well, then moving to a facility that's easier for the family to get to maybe not always be the most important concern any longer. The final decision regarding whether to make another move, depends on a variety of factors that families weighing carefully, with an important one being how difficult moves can be for elderly people.

We heard a number of stories of people deteriorating and needing to be put back on a waiting list for another level of care necessitating making new choices, and multiple moves over a fairly short period of time. This created challenges for some residents and families. Many family members described how confused and upset the resident was for a period of time after they moved into a new facility. The family also has to provide a lot of instrumental support around these moves, such as finding and/or storing furniture, and obtaining the right kinds of supplies. **Being able to move from one level of care to another within the same**

facility was described by some as ideal, but now seemingly impossible because of how the waitlist policies work.

The language that residents and their families used to describe their experience, even when the outcome was acceptable (i.e., a non-preferred option ended up working for them), illuminated the perceptions of the placement process. Phrases like: "the government put me here", "they told me where to go", and "I had no choice but to accept the bed, or s/he would be taken off the list" indicate that people felt like they didn't have much involvement in the decision-making process. These phrases do not resonate well with a common tag line for patient and family centred care, which is: "Nothing about me without me"^{viii}. **Ultimately then, it was the process – characterized by a lack of say and control, and uncertainty - that most people found most stressful and upsetting.** People expressed a desire for more support in making informed choices about their placement, to be placed where they choose to live, and if a placement is required in a non-preferred option that there is ongoing communication around the status of their move.

Finally, the findings from these interviews support what was learned through the literature review component of this project, which is that this transition from living at home to a continuing care setting can be difficult time (i.e., often characterized by feelings of loss related to independence, privacy, relationships, control and decision-making, and activity; and sometimes sadness, sorrow, angst and distress). A question going forward is how to develop placement processes that recognize and try to mitigate some of this, rather than exacerbate it. **As they currently stand, these policies often seem to work against concepts that health professionals and health systems espouse as important, such as: patient and family centred care^{ix} and continuity of care^x.** This can be difficult not only for residents and their families, but for the staff working in the healthcare system (i.e., in transition/placement services; in hospital and rehab facilities; in continuing care facilities) who want to do the best they can for their clients.

^{viii} Barry, M] and Edgman-Levitan, S (2012). Shared Decision-Making – The Pinnacle of Patient-Centered Care; NEJM, 366 (9), 780-781.

^{ix} Alberta Health Services South Health Campus describes patient and family centred care as: "building a culture of healthcare that arranges care around the patient and families, not the health system"...this includes involving "patients and families as full partners in care." (Retrieved Feb 2014 from: <http://www.albertahealthservices.ca/Facilities/SHC/page84.asp>)

^x Continuity of care can be defined as: "the degree to which a series of discrete healthcare events is experienced as coherent and connected and consistent with the patient's medical needs and personal context." Haggerty et al (2003). Continuity of Care: A multidisciplinary review. BMJ; 327(7425), 1219.

Appendices

Appendix A: Interview Guide

First Available Appropriate Living Option (FAALO) Policy Review

Qualitative research component: Talking to clients and their families

Interview Guide #1 (FAALO: for clients who could not be placed in one of their preferred choices directly)

Introduction

- Brief description of project and the purpose of these interviews
- Any questions
- Go over consent form

Questions

1. Could you please describe your (or your family member's) experience of your wait for and moving to a continuing care facility?

Probe around:

- The circumstances that led to the need for a move to a continuing care facility
 - Where they were waiting for the bed and how long (i.e., in hospital; at home; other)
 - The impact the wait had on their health (e.g., mental health, cognitive function) and wellbeing^{xi}
 - Where "home" is (before placement) and where family/friends live – rural community, town, city – get a sense of the geographic parameters
2. Do you recall an explanation about AHS's policies/rules regarding which continuing care facilities you might be moved to?
 - Who initially explained these policies/rules to you?
 - What was your understanding of these policies and how they work?
 - How was the distance parameter explained to you?
 - o If you were asked to move to a location that was not one of your preferred locations, what was your understanding of the distance of a site that you could be sent to while waiting for placement in one of your preferred options?
 - What was your understanding about how long you would stay at this location? Did you regard it as temporary or permanent?
 - Did you receive any written information about the policies?
 - Did you know who to contact if you had questions?
 3. How did you select your preferred location(s)?
 - Did you select more than one choice? If yes, how many?
 - What were the key factors that influenced your choice(s)?

^{xi} Recognizing that the transition from living at home to a continuing care setting can be difficult time (i.e., often characterized by feelings of loss related to independence, privacy, relationships, control and decision-making, and activity; and sometimes sadness, sorrow, angst and distress) (HQCA lit review).

Probe around: distance from home/family/friends; size of facility; reputation of facility; the accommodation (i.e., rooms, food); specialized care needs; care provided at the facility; activities available at the facility (e.g., exercise classes; games such as bridge; movie nights; music performances; other); services provided by the facility (e.g., hair/beauty salon; transportation to medical appts; local shopping trips; other trips)

4. What happened when you were asked to move to a temporary location you hadn't chosen?
 - Did this cause you concern or was the location acceptable?
 - If concerned, did you see if you could get this decision changed?
 - o Were you told about any appeal mechanism?
 5. What was your experience moving to this location that wasn't one of your choices?
 - Where were you/your loved one moved to? Did you have a partner, spouse or other close family member close by?
 - Did you get some help preparing for the transition to continuing care?
 - Did you understand that your stay there was temporary (i.e., that you were waiting there until a place at one of your preferred locations became available)?
 - What was your experience at this facility?
What was the impact on you, your family/friends?
- Probe around:** any harms - physical, mental, and/or emotional (e.g., separation of couples, including gay couples; depression; cognitive decline; weight loss); any hospital readmissions; any positive experiences
- How long did you have to wait in that location before one of your preferred sites became available? OR How long have you been waiting at that location (if person is still there)?
 - Did you ask for or receive any updates about when you might be moved?
6. Did you/will you move to one of your preferred sites (i.e., if/when one of their choices becomes available)? Why or why not?

Probe around:

- Whether facility exceeded their expectations (or not)
 - Whether they felt that a move would just be too disruptive
7. How did the move to your preferred site go? [If applicable]
 - What worked well
 - What didn't work as well
 - What was the impact on you, your family/friends (positive and/or negative)?

Probe around:

If multiple moves were required, ask about the impact of this on the client/family

8. Based on your experience, if you had to go through this process again, describe how you wished it would go? OR If you were making the rules that determine where people go to live in LTC, what would they be?
9. Is there anything else you want to tell us?

Thank you!

First Available Appropriate Living Option (FAALO) Policy Review

Qualitative research component: Talking to clients and their families

Interview Guide #2 (Non-FAALO: for clients who were placed in one of their preferred choices directly)

Introduction

- Brief description of project and the purpose of these interviews
- Any questions
- Go over consent form
- Advise of audio recording and seek consent

Questions

1. Could you please describe your (or your family member's) experience of waiting for and moving to a continuing care facility?

Probe around:

- The circumstances that led to the need for a move to a continuing care facility
- Where they were waiting for the bed (i.e., in hospital; at home; other)
- The impact the wait had on their health (e.g., mental health, cognitive function) and wellbeing^{xiii}
- Where "home" is (before placement) and where family/friends live – rural community, town, city – get a sense of the geographic parameters

2. Do you recall an explanation about AHS's policies/rules regarding which continuing care facilities you might be moved to?

- Who initially explained the policies/rules to you?
- What was your understanding of the policies/rules and how they work?
- How was the distance parameter explained to you?
- Did you receive any written information about the policies?
- Did you know who to contact if you had questions?

3. How did you select your preferred location(s)?

- Did you select more than one choice? If yes, how many?
- What were the key factors that influenced your choice(s)?

Probe around: distance from home/family/friends; size of facility; reputation of facility; the accommodation (i.e., rooms, food); specialized care needs; care provided at the facility; activities available at the facility (e.g., exercise classes; games such as bridge; movie nights; music performances; other); services provided by the facility (e.g., hair/beauty salon; transportation to medical appts; local shopping trips; other trips)

4. What was your experience moving to one of your preferred locations?

- Were you moved to your first choice, or another choice?

^{xiii} Recognizing that the transition from living at home to a continuing care setting can be difficult time (i.e., often characterized by feelings of loss related to independence, privacy, relationships, control and decision-making, and activity; and sometimes sadness, sorrow, angst and distress) (HQCA lit review).

- Where were you/your [loved one] moved to? Did you have a partner, spouse or other close family member close by?
- Did you get some help preparing for the transition to continuing care?
- What was the initial move like?
- Overall, how was/is your experience living at this facility?
- What was/is the impact on you, your family/friends?

Probe around: any harms (physical, mental, and/or emotional); any positive experiences

5. Did you stay at and/or are you planning to stay at this location? Why or why not?

Probe around:

- if this was not their first choice, whether they are planning to try and move to one of their other choices?
 - Whether their expectations about the facility were met or exceeded or not met?
 - Whether they felt that a move would just be too disruptive
6. Based on your experience, If you had to go through this process again, describe how you wished it would go? OR If you were making the rules that determine where people go to live in LTC, what would they be?
7. Is there anything else you want to tell us?

Thank you!

Appendix B: Consent Form

Title of Project: Continuing Care Waitlist Policy - First Available Appropriate Living Option (FAALO) Review

Name of Project Leads: Anette Mikkelsen and Carmella Duchscherer, Health Quality Council of Alberta

Please initial box

- 1 I confirm that I understand the above project. I have had the opportunity to ask questions about the project and have had these answered satisfactorily. ☐

- 2 I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my health care or my legal rights being affected. ☐

- 3 I understand that the data collected through this project will only be looked at by members of the study team. My name will not be included in any of the study reports or presentations. ☐

- 4 I understand that I will be asked my permission to have the interview audio-recorded, but that I am free to refuse this request and still participate in the interview. ☐

- 5 I agree to be interviewed for this project. ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Project Team Member	Date	Signature

One copy to be kept with the Health Quality Council of Alberta

Appendix VI: Key documents

Year	Month	Author	Key documents
1988	February	Committee on Long Term Care for Senior Citizens - Dianne Mirosh	A New Vision for Long Term Care – Meeting the Need Recommended that “province wide implementation of single point of entry be encouraged when possible”
1989	August	Alberta Health	Voluntary Province-Wide Implementation of Single Point of Entry for Long Term Care Services Discussion Paper
1990	May	Alberta Health	“Program Description: Single Point of Entry for Long Term Care Services” - Working document - Provided guidelines for implementation of the Single Point of Entry process
1993	August	Alberta Health	Single Point of Entry for Long Term Care Services in Alberta – Program Description - Revised and updated version of the 1990 document - Rights and dignity of individuals are respected during all stages of the single entry process, including the right to express choice regarding the type and location of Long term care services - Priority given to individuals with the greatest need as determined by the assessment - Identified 'the individual is willing to accept the first available bed in the region' - Individuals have the right to appeal
1997		Health regions in Alberta	First Available Bed Policies developed in Calgary Health Region and Chinook Health Region Others followed in 1998 (Peace); 1999 (Capital); 2006 (Aspen and David Thompson); 2008 (East Central). Palliser and Northern Lights had no formal policies.
1999	November	Alberta Health	Healthy Aging: New Directions for Care Part One: Overview¹ Long Term Care Review: Final Report of the Policy Advisory Committee (Broda Report)
2000	April	Alberta Health	Strategic Directions and Future Actions, Healthy Aging and Continuing Care in Alberta² - Shift to the new vision and principles for continuing care - Implement the recommendations of the Long Term Care Review Policy Advisory Committee (Broda Report)
2000	April	Alberta Health	Healthy Aging: New Directions for Care - Public and Stakeholder Response to the Final Report of the Long Term Care Policy Advisory Committee³
2002		Alberta Health	Tracking Progress a Progress Report on Continuing Care Reform in Alberta⁴ Reports progress on the strategic directions set out in <i>Strategic Directions and Future Actions: Healthy Aging and Continuing Care in Alberta</i>
2005		Alberta Health Services	Strategic Innovations for the 21st Century: Beyond Home Care to Community Care Discussion paper

Year	Month	Author	Key documents
2005	November	Alberta Health	Achieving Excellence in Continuing Care - Final Report of the MLA Task Force on Continuing Care Health Service and Accommodation Standards⁵
2008	May	Alberta Health	Announcement of the creation of Alberta Health Services with one provincial governance board to replace the 12 formerly separate health entities in the province: nine geographically based health authorities and three provincial entities ⁶
2008	July	Alberta Health	Continuing Care Health Service Standards^{7(p 2)} to identify standards for the provision of quality continuing care health services that take into consideration the individual needs, preferences and abilities of each client
2008	December	Alberta Health	Vision 2020 The Future of Health Care in Alberta Phase One^{8(p 4)} Too many continuing care patients are being cared for in hospitals. This backs up admissions throughout the hospital and delays emergency room admissions and hospital services for people needing scheduled surgical procedures
2008	December	Alberta Health	Provincial Service Optimization Review: Final Report^{9(p 5)} - Conducted by McKinsey and Company - Recommendation 2: Shift elected services from LTC to supportive living and home care; Invest in developing additional supportive living spaces and home care capacity to keep patients closer to home and make their experience more satisfactory; Reduce barriers to using these types of care; Conduct analyses on an expedited time frame to determine what level of LTC facility investment is optimal
2008	December	Alberta Health	Continuing Care Strategy - Aging in the Right Place¹⁰ Strategy intended to provide new ways of delivering services, offering more choice to Albertans in their homes and communities
2010	March	Alberta Health Services	AHS Board Meeting – Request for approval of the document “ Progressing the Continuing Care Strategy: the Right Care in the Right Place ” – the three year continuing care capacity plan. ¹¹ - Motion to approve unanimously carried - Board Meeting Minutes: This strategy will be reviewed by AHW and released at a later date
2010	April	Government of Alberta, Alberta Health and Alberta Health Services	Co-ordinated Access to Publicly funded Continuing Care Health Services: Directional and Operational Policy - Identifies the directional and operational policies needed to move Co-ordinated Access forward to ensure it supports new models of care and accommodates increased personal choice - Prepared in support of the Continuing Care Strategy: Aging in the Right Place
2010	November	Government of Alberta and Alberta Health Services	Becoming the Best - Alberta's 5 year Health Action Plan 2010 - 2015¹² - Strategy 2 – Providing More Choice for Continuing Care - Adding at least 2300 continuing care spaces (by March 2012) - Add 3000 more continuing care spaces (by March 2015) - Develop and start to implement a 5 year plan for continuing care. The plan will describe the full continuum of continuing care from home care to LTC and will include capital plans and new ways of delivering continuing care services (by March 2012) - Review and update the plan for continuing care annually

Year	Month	Author	Key documents
2010	November	Government of Alberta	Aging Population Framework¹³ Alberta Seniors and Community Supports will facilitate implementation of the Aging Population Policy Framework and the co-ordinated development of policies, programs and supports consistent with the Framework
2011	April	Alberta Health Services	Governance Document Framework Clinical and Corporate¹⁴ Prepared by: Clinical Policy Department and Corporate Policy Department
2012	March	Alberta Health Services	Action on: Seniors Care The Right Care in the Right Place - Update¹⁵ 2157 spaces of the 2300 were opened as of March 31, 2012. The remainder was expected to be opened by summer 2012.
2012	April	Alberta Health Services	Publicly reported 'percentage of people placed within 30 days' as a Tier 1 performance measure^{16(p64)}
2013		Alberta Health Services and Alberta Health	Continuing Care Capacity Needs Assessment 2013 – 2032 Forecasts demand for all continuing care services (LTC, SL4D, SL4, SL3 and LTHC) combined over a 20 year horizon (2013 – 2032)
2013	January – March	Alberta Health Services	Pilot of the AHS policy " Wait list: First Available Appropriate Living Option " in Calgary and Edmonton to be completed prior to final approval and province-wide implementation of the policy. Evaluation report submitted March 25, 2013
2013		Alberta Health Services	Alberta Health Services Health Plan and Business Plan 2013 – 2016 Better Quality, Better Outcomes, Better Value.¹⁷ - Currently Alberta's publicly funded health system spends over \$1 billion a year on continuing care - AHS will continue to work with Alberta Health to execute the Continuing Care Plan - New investments include the Continuing Care Capacity Plan
2013	May	Alberta Health Services	Dr. Eagle and Dave O'Brien speak to the Legislative Standing Committee on Public Accounts regarding the 100 km policy^{18(p 164)}
2013	May	Alberta Health Services	AHS requested an internal review of the FAALO policies: - Continuing care wait list management: first available appropriate living option Level 1 Policy – May 8, 2013 - Continuing care wait list management: prioritization Level 1 Policy – May 8, 2013 AHS QI working group established to conduct the review and the Project Charter developed

Year	Month	Author	Key documents
2013		Alberta Health	2012/2013 Annual Report¹⁹ Includes performance measures and targets for continuing care ▪ Number of persons waiting in an acute/sub-acute hospital bed for continuing care as of March 31, 2013 Actual: 453 Target: 350 ▪ Number of persons waiting in the community for continuing care as of March 31, 2013 Actual: 701 Target: 850
2013	June	Government of Alberta and Alberta Health Services	News Release – Alberta takes action to improve care²⁰ ▪ The 'first available bed' policy, which required continuing care residents to accept a placement within 100 kilometres of their home, is withdrawn effective immediately
2013	October	Alberta Health Services	Final report of AHS QI working group with recommendations ▪ Data for 494 clients was collected: approximately 100 clients from each zone. Captured utilization of FAALO, distance between FAALO and first choice and length of stay in FAALO space prior to moving to first choice

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Appendix VII: Glossary

Accommodation rate	SL – residents pay accommodation charges for services such as meals, housekeeping, and building maintenance. AH determines the maximum DSL charges for private rooms and for semi-private rooms as well as maximum charges for the three types of LTC accommodation i.e. private room, semi-private room, standard room. On September 1, 2013 the maximum accommodation charges for DSL were: Private room - \$58.70 per day (average monthly maximum of \$1,785) Semi-private room - \$50.80 per day (average monthly maximum of \$1,545)
Continuing Care	Continuing Care is an integrated range of services supporting the health and wellbeing of individuals living in their own home or in a supportive living or long-term care setting. Continuing care clients are not defined by age, diagnosis or the length of time they may require service, but by their need for care.
Co-ordinated Access	Describes a province wide, person centred, integrated service access and delivery approach that provides Albertans with reasonable, timely, appropriate access to publicly funded continuing care health services based on availability and determination of unmet need.
Continuing Care Living Options:	Including three levels of living options: home living, supportive living and facility living (long-term care).
Supportive Living Options	Supportive living combines accommodation services with other supports and care. It meets the needs of a wide range of people, but not those with highly complex and serious health needs. In addition to providing a place to live, accommodation services in supportive living accommodations can include meals, housekeeping and social activities. Supportive living residents can also receive professional and personal support services through home care.
SL3	Environment that provides 24-hour on-site scheduled and unscheduled personal care and support provided by Healthcare Aides. Some settings may have a secured environment. Professional health services including Registered Nurse services with 24-hour on-call availability, case management, assessment and other consultative services such as but not limited to Geriatric/Psychogeriatric Outreach Teams, Palliative Care, Social Work, Rehabilitation Services, etc. are provided through AHS.

- SL4** Environment that provides 24-hour on-site scheduled and unscheduled professional and personal care and support, provided by Licensed Practical Nurses and Healthcare Aides.

Professional services including Registered Nurse services with 24 hour on-call availability, case management, assessment and other consultative services such as but not limited to Geriatric/Psychogeriatric Outreach Teams, Social Work, Rehabilitation Services etc. are provided through AHS.

- SL4D** A designated Supportive Living Level 4 Dementia – enhanced assisted living provides a purposeful home-like design with small groupings of private bedrooms and associated spaces in a secured therapeutic environment. This environment provides 24-hour on site scheduled and unscheduled professional and personal care and support provided by Licensed Practical Nurses and Healthcare Aides.

Professional health services including Registered Nurse services with 24-hour on-call availability, case management, assessment and other consultative services such as but not limited to Geriatric/Psychogeriatric Outreach Teams, Social Work, Palliative Care, Rehabilitation Services etc. are provided through AHS.

- Long-term Care** Long-term Care Facility is an environment that provides for people with complex, unpredictable medical needs requiring 24-hour on site Registered Nurse assessment and/or treatment. In addition, professional services may be provided by Licensed Practical Nurses and 24-hour on site unscheduled and scheduled personal care and support will be provided by Healthcare Aides.

Case management/Registered Nurse and Rehabilitation Therapy are provided on site. Other consultative services such as but not limited to Geriatric/Psychogeriatric Outreach Teams, Palliative Care, etc. are provided through AHS. Long-term facility care may have secured long-term care, dementia care units.

Operations management	Operations management oversees all activities directly related to making a product or providing a service. This functional area is responsible for the processes that transform or convert inputs of materials, equipment, energy, information, and human skills into goods and services that satisfy customer needs.
Single point of entry	'precursor' to co-ordinated access. Was a model initiated in Alberta in the 1980's to provide a way for people to access all long-term care services through one entry point. All people entering the long-term care system would have a standard assessment completed by a Home Care Assessor.

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